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ABSTRACT

Statistics on the current status and the changing patterns of services for persons with developmental disabilities are presented in graphic, tabular, and narrative form. The volume summarizes national statistics gathered through the Ongoing Data Collection System of the Administration on Developmental Disabilities and other sources of national data. The volume is divided into seven major topical areas: (1) Where do people live? (2) What are the characteristics of people receiving residential service? (3) Where are children and youth educated? (4) Where do people work? (5) How are people with disabilities and their families being empowered? (6) What are the outcomes of community living? and (7) How much do services cost? Over 40 sources for statistics are listed. (JDD)

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1990 Yearbook

Services for People with Developmental Disabilities

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1990 Chartbook

Services for People with Developmental Disabilities

Center for Residential and Community Services

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FOREWORD

The 1990 Chartbook on Services for Persons with Developmental Disabilities is intended to provide a picture of the current status and the changing patterns of services for persons with developmental disabilities. It summarizes statistics gathered through the Ongoing Data Collection System of the Administration on Developmental Disabilities (ADD) and other sources of national data. Projects making up ADD's Ongoing Data Collection System are currently housed within the University Affiliated Program on Developmental Disabilities at the University of Illinois at Chicago (expenditures), Boston Children's Hospital (employment and employment services) and the University of Minnesota (residential services).

The statistics provided in this volume show clear trends toward increased participation of citizens with developmental disabilities in community programs. The passage of the Americans with Disabilities Act foretells of a new societal perspective on people with disabilities. America as a whole is beginning to recognize that citizens with disabilities have civil rights, that they are more often defeated by discrimination than by their functional limitations, and that their right to choose their own life styles is as basic as our Constitution. The individuals reflected in these statistics have shown us all that there can be a place in the community for all people with developmental disabilities. Yet these same statistics show that there is much left to be accomplished, and that, indeed, what is left to be accomplished will often present new and more difficult challenges for people with developmental disabilities and the people who provide services and supports to them. But with continued national commitment to the independence, productivity and integration of persons with developmental disabilities, I am convinced that future statistics of the ADD Ongoing Data Collection System and related national data collection programs, will show continued evidence of substantial growth in community-based services and supports for persons with developmental disabilities. The Administration on Developmental Disabilities, its staff and its programs remain fully committed to such ends.

Deborah L. McFadden, Commissioner
Administration on Developmental Disabilities

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PREFACE

This Chartbook summarizes national statistics on services for persons with developmental disabilities. It is similar to the 1982 *Sourcebook on Long-Term Care for Developmentally Disabled Persons*, prepared by the Center for Residential and Community Services, although somewhat expanded in its scope. The purpose of this Chartbook is to provide the most recent and reliable statistics available that can serve as basic indicators of the status and changing patterns of services to persons with developmental disabilities. This has been done primarily in graphical presentations with a minimum of description and discussion. Source notes accompanying each chart refer the reader to specific documents from which the reported statistics were drawn.

The Chartbook has been divided into 7 major topical areas: 1) Where do people live? 2) What are the characteristics of people receiving residential services? 3) Where are children and youth educated? 4) Where do people work? 5) How are people with disabilities and their families being empowered? 6) What are the outcomes of community living? 7) How much do services cost?

Most of the statistics reported were drawn from the projects in the ADD Ongoing Data Collection System at the University of Illinois at Chicago, Boston Children's Hospital and the University of Minnesota. Important statistics were also obtained from the U.S. Department of Education, the Rehabilitation Research and Training Center at Virginia Commonwealth University, and the Human Services Research Institute.

We are grateful to all who assisted us with the statistics reported here. We are particularly appreciative of Rick Hemp's thoughtful help with statistics and Vicki Gaylord's with design. We also thank Cheryl Morgan for her assistance in the preparation and layout of this report. We acknowledge the much valued continued support of the Administration on Developmental Disabilities for our particular project and for the Ongoing Data Collection System as a whole. We hope this product reflects some of the depth and quality of this particular statistical program and of other complementary national data collection programs.

INTRODUCTION: Who are the people with developmental disabilities?

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 defined a developmental disability as a severe, chronic condition that:

1. is attributable to a mental and/or physical impairment;
2. is manifested before age twenty-two;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living
 - economic self-sufficiency
5. reflects a need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned or coordinated.

Unfortunately there is no adequate basis currently available to estimate the size and characteristics of the group of people meeting this definition. There is no generally accepted standard for what constitutes a "substantial functional limitation" in the 7 major life areas outlined above, as there is, for instance, with "significantly sub-average intelligence" in the definition of mental retardation (i.e., an I.Q. more than 2 standard deviations below average). Even if there were consensus on what constitutes "substantial functional limitations," there is no national or state level data base permitting reliable estimates of such limitations among the general population.

Because of the lack of standard criteria for applying the definition of developmental disability and the lack of relevant data on the occurrence of functional limitations within the general population, estimates of the prevalence of developmental disabilities range widely. State

Developmental Disabilities Planning Councils use a variety of estimates, most of which range between 1% and 2%.

Statistics from household surveys in Western nations are fairly consistent in estimating that about 1% of the population is recognized at any one time as having mental retardation; although among adults who are no longer in school, the percentage is lower (Lakin, Hill, & Bruininks, 1985). But there are wide variations in estimates of the proportion of people with mental retardation within the broader category of people with developmental disabilities. Relatively low estimates, as low as 35%, tend to be based on the aggregate prevalence of the different conditions traditionally associated with the term developmental disability (mental retardation, cerebral palsy, autism, epilepsy and others). Relatively high estimates, 90% or higher, tend to be based on the actual number of people with mental retardation among all users of services provided by "developmental disabilities" programs. The first type of estimate assumes, often erroneously, that virtually all people with certain types of conditions have "substantial functional limitations." The second type of estimate assumes, often erroneously, that persons with all kinds of conditions leading to substantial functional limitations are provided or desire access to the "developmental disabilities" service systems.

This last point introduces a limitation of the coverage of this Chartbook. The service utilization and cost data presented here are focused primarily on state developmental disabilities agencies, which are much more likely to serve people with disabilities that include or are associated with mental retardation (e.g., cerebral palsy and autism). Persons with physical and health impairments, but without intellectual impairments, are much less likely to receive or, for that matter, want services from such agencies, and are relatively more likely to be served by health and/or general public assistance agencies. Because state developmental disabilities agencies focus their services primarily on persons with conditions associated with mental retardation, reference is made throughout this Chartbook to persons with mental retardation and related developmental disabilities (MR/DD).

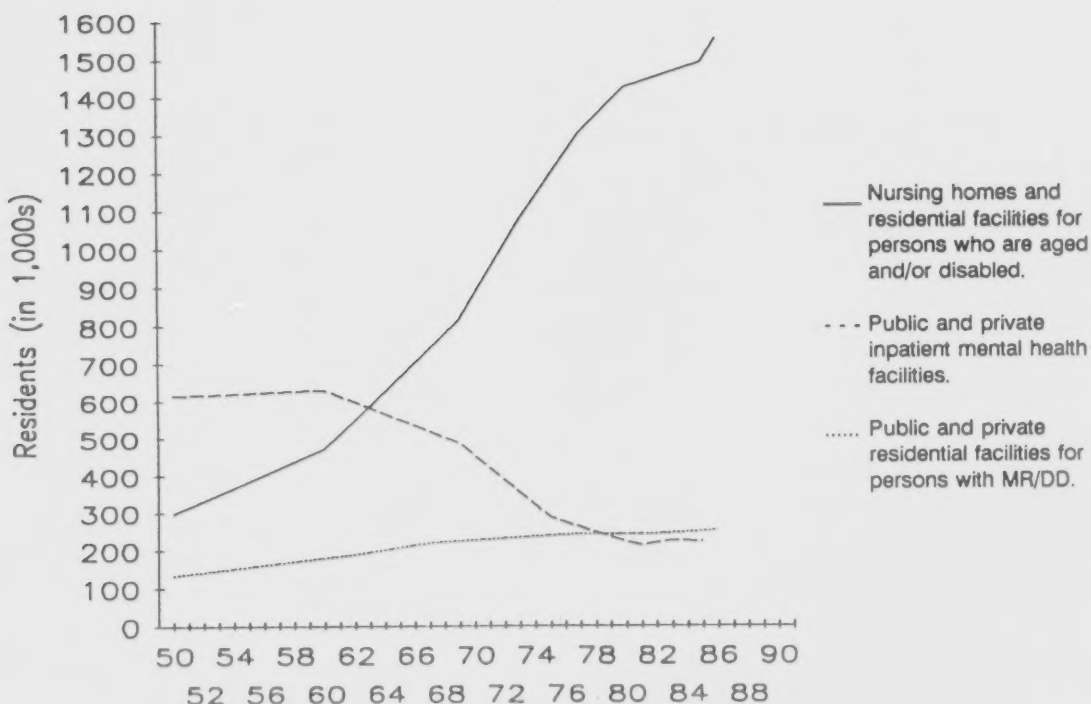
PART I: Where do people live?

The provision of residential services to persons with mental retardation and related developmental disabilities (MR/DD) has changed dramatically in the last 25 years. A primary feature of this change is the dramatic decline in the population in large public institutions--from an average daily population of about 195,000 residents in 1967 to an average of about 87,000 in 1989. To show the magnitude of change, in 1967, 85% of the people in residential facilities for people with MR/DD were in large state MR/DD facilities; in 1988 only 34% were. Even more dramatic has been the decrease in the number of people with a primary diagnosis of mental retardation in state and county psychiatric units. These populations decreased from almost 37,000 in 1960 to about 2,000 in 1988.

As the number of persons with MR/DD in public institutions has decreased, the number living in private, community-based housing of 15 and fewer residents has steadily increased. That population more than tripled from about 40,000 in 1977 to over 125,000 in 1988. In 1988 states reported and national surveys estimated that there were about 330,000 total persons with MR/DD in MR/DD residential facilities and foster homes, psychiatric facilities and nursing and personal care homes nationwide. That represents less than .15% of the U.S. population. Even using a conservative estimate that 1% of the U.S. population has developmental disabilities, this would indicate that about 85% of persons with developmental disabilities are living with their own families or are otherwise living on their own, independent of the publicly supported residential care system.

As the statistics on the contemporary status and trends in residential services for persons with MR/DD in this section are examined, it is important to remember that the people receiving these services represent an important, but distinct minority of all persons with developmental disabilities.

Figure 1.1 Residential Services for Persons with Mental Retardation and Related Developmental Disabilities in the Context of the Three Major Long-Term Care Systems, 1950-1986

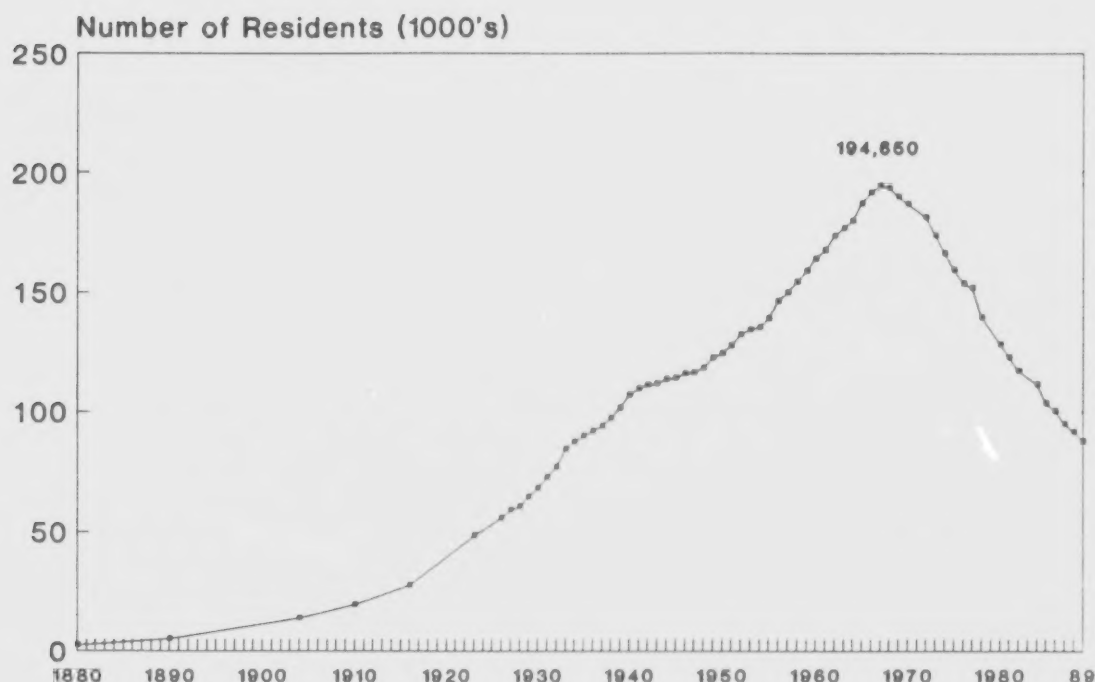


Providing long-term care for persons with disabilities is a huge and costly social enterprise. The total population of persons with disabilities who receive long-term care in the United States numbers nearly 2 million, for whom annual expenditures are over 50 billion dollars. Not only has the system of long-term care grown dramatically in recent decades, it has also undergone some dramatic shifts in the relative size of the various components of the total system of long-term care settings.

In 1950 there were twice as many people in psychiatric facilities (mental hospitals) as in facilities for aged and disabled persons. Since then, however, there has been a steady decline in the population of psychiatric facilities and a steady growth in facilities for aged/disabled populations. In contrast with the dramatic reversal of the predominant role of nursing homes and psychiatric facilities in the long-term care system, the total number of persons served in facilities for persons with mental retardation and related developmental disabilities shows remarkable stability.

(Source: Zappollo, Lakin, & Hill, 1990)

Figure 1.2 People with Mental Retardation and Related Developmental Disabilities in Public Mental Retardation Institutions (1880-1989)



From the founding of the first institution for persons with mental retardation in the wing of a state school for blind children in Massachusetts in 1848, public institutions for persons with mental retardation and related developmental disabilities (MR/DD) grew steadily in their populations through 1967. In Fiscal Year 1968 the average daily population of these institutions decreased for the first time in history, falling from 194,650 to 193,690. A steady decrease of from 3%-6% has been evident every year since. On June 30, 1989 there were 88,112 people residing in state MR/DD institutions, the lowest number since 1934.

Of course, the relative placement rate (residents of MR/DD facilities per 100,000 of the general population) has decreased even more rapidly. In FY 1989 there was an average of 34.8 residents of state MR/DD facilities per 100,000 of the general population. This compares with a placement rate of 98.6 in 1967 and an estimated rate of 34.0 in 1919, when state institutions housed a total of about 38,000 persons with MR/DD.

(Sources: Lakin, 1979; Scheerenberger, 1990; White, Lakin, & Bruininks, 1990)

Figure 1.3 Number of People with Mental Retardation and Related Developmental Disabilities in Different Supervised Housing Arrangements in 1988

Residential options for people with mental retardation and related developmental disabilities have been expanded significantly in the last 20 years. The growing variety of smaller, community-based facilities has been the primary contributor to this greater overall variety. The nine basic types of supervised housing available for people with MR/DD include those described below.

*Generic foster care homes** provide services to persons with mental retardation and related developmental disabilities under regular foster care licenses. *Specialized foster care homes* operate under special licenses or contracts from states or regions to provide services to persons with developmental disabilities. *Semi-independent or supported living* arrangements serve residents who live on their own with less than full-time supervision and support. The *nonstate group residences (15-)* are staffed residential facilities operated by private or local government agencies to provide care, supervision and training to 15 or fewer people. *Nonstate institutions (16+)* are group residences with 16 or more residents operated by nonstate agencies. *State-operated group residences (15-)* are staffed facilities operated by the state to provide care, supervision and training to 15 or fewer people. *State MR/DD institutions* are state-operated group residences for 16 or more persons with MR/DD, including special MR/DD units in other types of state-operated facilities which have 16 beds or more. *State MI institutions** are state psychiatric hospitals which serve persons with MR/DD in other than separately operated MR/DD units. *Nursing homes* are facilities offering medical, nursing or personal care to persons with MR/DD, but which are not specifically licensed for persons with MR/DD.

In 1988 the total number of persons in nonstate MR/DD group facilities of 15 or fewer residents was almost as large as the number of persons in large state MR/DD institutions (84,293 compared to 91,703). The total number of persons in all nonstate MR/DD facilities (171,414) greatly exceeded the number in all state facilities (99,327).

The reported number of persons with MR/DD in each of these types of facilities in June 1988 (or the closest date as indicated in the footnote) was:

Generic Foster Care*	13,981	(children only) ^a
Specialized MR/DD Foster Care	23,568	(children & adults) ^b
MR/DD Semi-Ind. & Supported Living	17,646	
Nonstate MR/DD Group Residences (15-)	84,293	
State-Operated MR/DD Group Residences (15-)	5,654	
Nonstate MR/DD Institutions (16+)	45,907	
State MR/DD Institutions (16+)	91,703	
State MI Institutions*	1,970	
Nursing Homes*	45,843 ^c	

* indicates facilities that are not considered "MR/DD" facilities.

^a December 31, 1985.

^b California foster care residents estimated to be the same as reported in the 1982 National Census of Residential Facilities (Hauber et al., 1984).

^c Estimates from early 1987.

(Sources: Center for Residential and Community Services, 1990; Hill, Lakin, Novak, & White, 1987; Lakin, Prouty, White, Bruininks, & Hill, 1990; Lakin, White, Hill, Bruininks, & Wright, 1990; White, Lakin, & Bruininks, 1989)

Number of People with MR/DD in Different Supervised Housing Arrangements in 1988

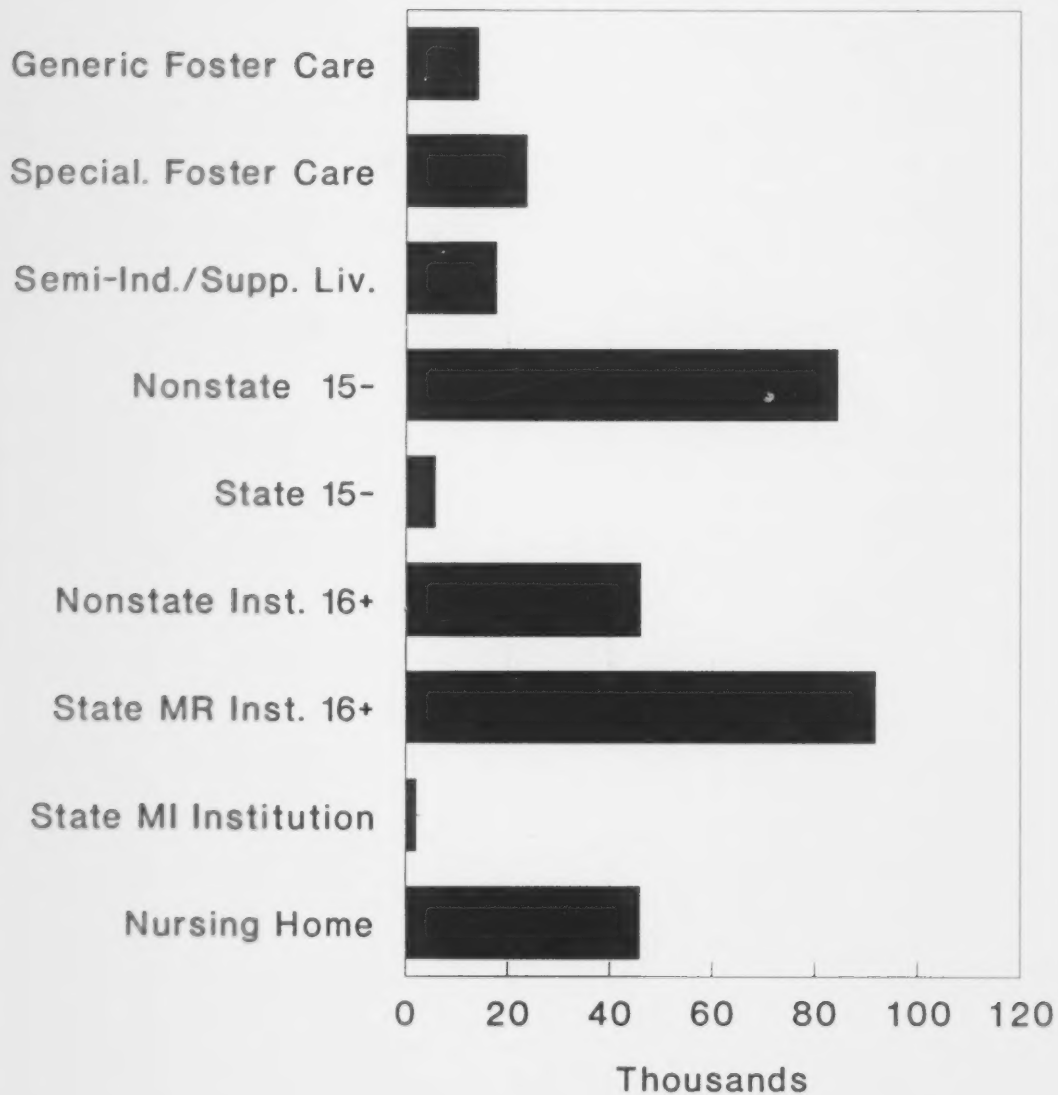


Figure 1.4 Changing Placement Patterns for Persons with MR/DD, 1967-1988

Over the past two decades there have been major changes in the utilization of different types of residential settings for persons with mental retardation and related developmental disabilities (MR/DD). These changes have occurred despite only modest increases in the total number of people with MR/DD in different types of residential care. For example, between 1967 and 1988, persons with MR/DD receiving residential care in all state-operated mental retardation and psychiatric facilities, all nonstate MR/DD facilities, all nursing homes and all foster homes increased only 8%, from approximately 304,000 persons in 1967 to 330,500 in 1988. This increase in the total population served occurred exclusively between 1967 and 1977.

Several of the major changes that have occurred in the distribution of persons with MR/DD among residential options with different models of operation are shown in Figure 1.4. For example, there was a seven-fold increase in the use of all types of nonstate (overwhelmingly private, but also local government) MR/DD facilities, including specialized MR/DD foster care. This increase was from about 24,000 total residents in 1967 to 171,000 residents in 1988. This increase was accompanied by a decrease in the use of state operated MR/DD residential facilities, from 194,650 persons in such facilities in the high-point year of 1967 to 97,357 in 1988. The statistics on state-operated MR/DD facilities include both state-operated group homes of 15 and fewer residents and special MR/DD units on the grounds of traditional state psychiatric (MI) facilities. There was also a dramatic reduction in the number of persons with MR/DD in public psychiatric institutions (excluding special MR/DD units), from 34,000 in 1967 to 1,970 in 1988. The number of persons, usually children, in generic foster care has remained approximately the same since 1967, while the number of persons with MR/DD in nursing homes has increased slightly, from an estimated 33,000 (based on 1973-1974 estimates) to 46,000 over the twenty-year period.

Certain of the population trends shown in Figure 1.4 are even more dramatic when expressed as total residents with MR/DD per 100,000 of the general U.S. population, that is, when the placement statistics are controlled for growth in the U.S. population from 1967 to 1988. Although from 1967 to 1988 the total number of persons with MR/DD in the various residential settings increased by 8%, the number of residents per 100,000 of the general population decreased from 154 per 100,000 to 134.5 per 100,000 (a 12.7% decrease). In 1967 there were 99.7 persons with MR/DD in state mental retardation facilities of all sizes and 18.1 persons in state psychiatric facilities per 100,000 of the general U.S. population. In 1988 there were 39.6 persons with MR/DD in state mental retardation facilities of all sizes and 0.8 persons with MR/DD in state psychiatric facilities per 100,000 of the general population.

(Sources: Hill, Lakin, Novak, & White, 1987; Lakin, Hill, & Bruininks, 1985; Lakin, Bruininks, Doth, Hill, & Hauber, 1982; Lakin, Prouty, White, Bruininks, & Hill, 1990; Lakin, White, Hill, Bruininks, & Wright, 1990).

Changing Placement Patterns for Persons with MR/DD, 1967 - 1988

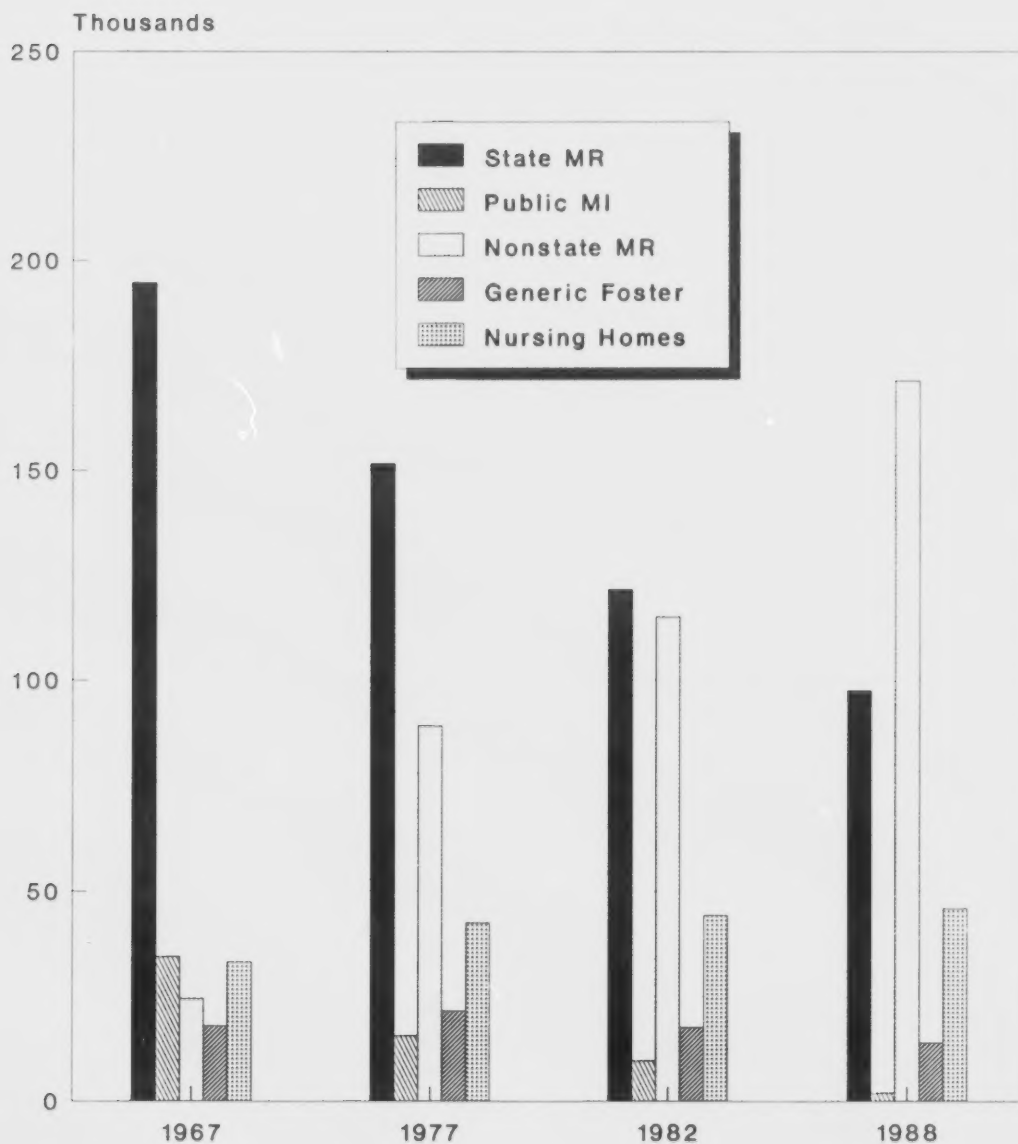


**Figure 1.5 Change in the Number of Persons with MR/DD in Different Residential Settings
Between 1977 and 1988**

Between June 30, 1977, and June 30, 1988 there were substantial changes in the places of residence of persons with mental retardation and related developmental disabilities (MR/DD). However, the total number of individuals with MR/DD in residential care facilities changed very little over the 11 year period. In 1977 various surveys indicated that there were an estimated 331,726 persons with MR/DD in the various residential facilities shown in Figure 1.4. In 1988, the number of people with MR/DD in the same types of residential facilities was 330,475. The primary factor in this general stability in the size of the total population of people in residential care in the face of the increasing general population of the United States has been the dramatic decrease in the number of children and youth living in out-of-home residential placements. (This is shown in detail in Figures 2.1, 2.2 and 2.3.)

While the total population of persons with MR/DD in residential facilities has been remarkably stable, the distribution of residents among the different types of housing has changed substantially. The most notable change is the decrease in state institution populations (from 151,532 to 91,703 residents), and the increase in small nonstate group home populations (from 32,407 to 90,391 residents).

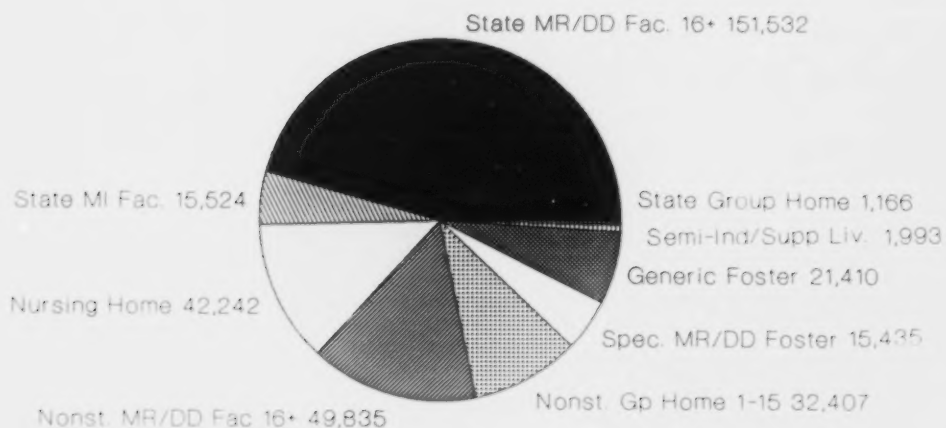
Another program model showing substantial growth is semi-independent/supported living, which increased from about 2,000 residents in 1977 to over 17,600 in 1988. State psychiatric facilities reported an almost equally rapid decrease, from 15,500 to about 2,000 residents in their general population. The statistics on psychiatric facility residents exclude people in special MR/DD units, which are considered MR/DD institutional settings in this report. It should be recognized that some of the reported decrease in population with psychiatric facilities resulted from the development of special MR/DD units for persons with MR/DD already living in those facilities.

A number of facility types showed relatively little population change between 1977 and 1988. Large nonstate facilities had a population decrease from 49,800 to 45,900. Nursing homes had an increase in residents with mental retardation and related developmental disabilities from an estimated 42,200 to 45,800, the latter statistic for 1987 based on the 1987 National Medical Expenditure Survey. Among all foster homes (both generic and specialized), estimated populations increased only slightly from 36,800 to 37,500. However among these same foster homes there was some shift from generic foster homes without special MR/DD licensing to foster homes with special licenses or contracts to serve persons with MR/DD. Although still serving less than 2% of persons with MR/DD in 1988, small state-operated group homes grew rapidly between 1977 and 1988, from about 1,200 total residents in 1977 to nearly 5,700 in 1988.

(Sources: Center for Residential and Community Services, 1990; Hill, Lakin, Novak, & White, 1987; Lakin, Hill, & Bruininks, 1985; Lakin, Prouty, White, Bruininks, & Hill, 1990; Lakin, White, Hill, Bruininks, & Wright, 1990; White, Lakin, & Bruininks, 1989)

Change in the Number of Persons with MR/DD in Different Residential Settings Between 1977 and 1988

June 30, 1977



June 30, 1988

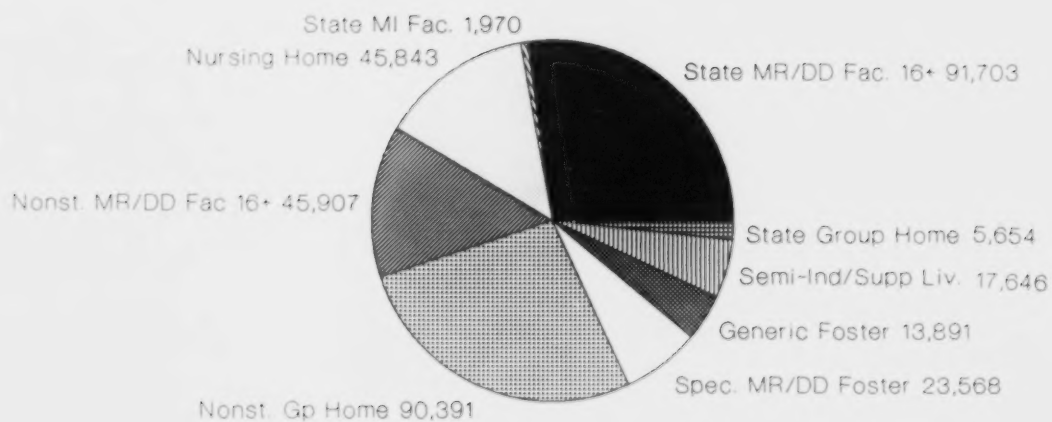
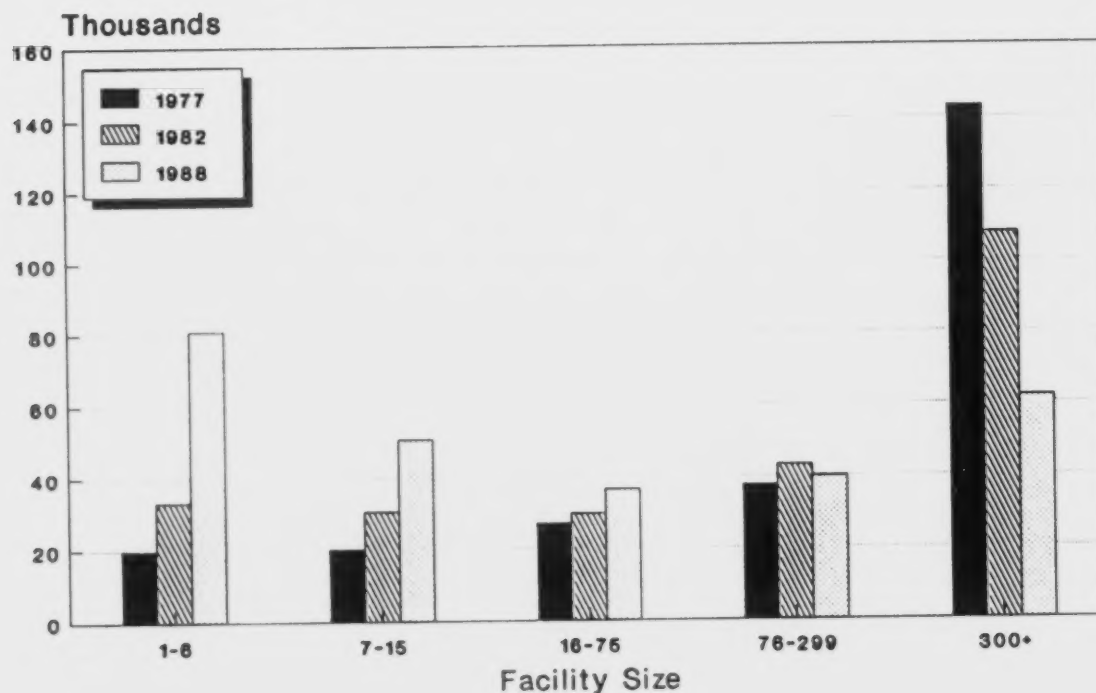


Figure 1.6 Number of Residents of MR/DD Facilities by Size in 1977, 1982, and 1988



The number of persons living in different sizes of MR/DD residential facilities has changed substantially in the past 11 years (see Figure 1.3 for specification of MR/DD facilities). The most dramatic changes in population have come in the largest facilities of 300 or more residents and the smallest facilities of 6 or fewer residents. The number of persons in 1-6 resident settings quadrupled between 1977 and 1988, from approximately 20,000 to 80,000 persons. In 1988, there were more persons with mental retardation/developmental disabilities in placements with 6 or fewer residents than in facilities with 300 or more residents. The number of persons in all facilities of 15 or fewer residents was approximately 131,000, compared to 137,000 in facilities with 16 or more residents.

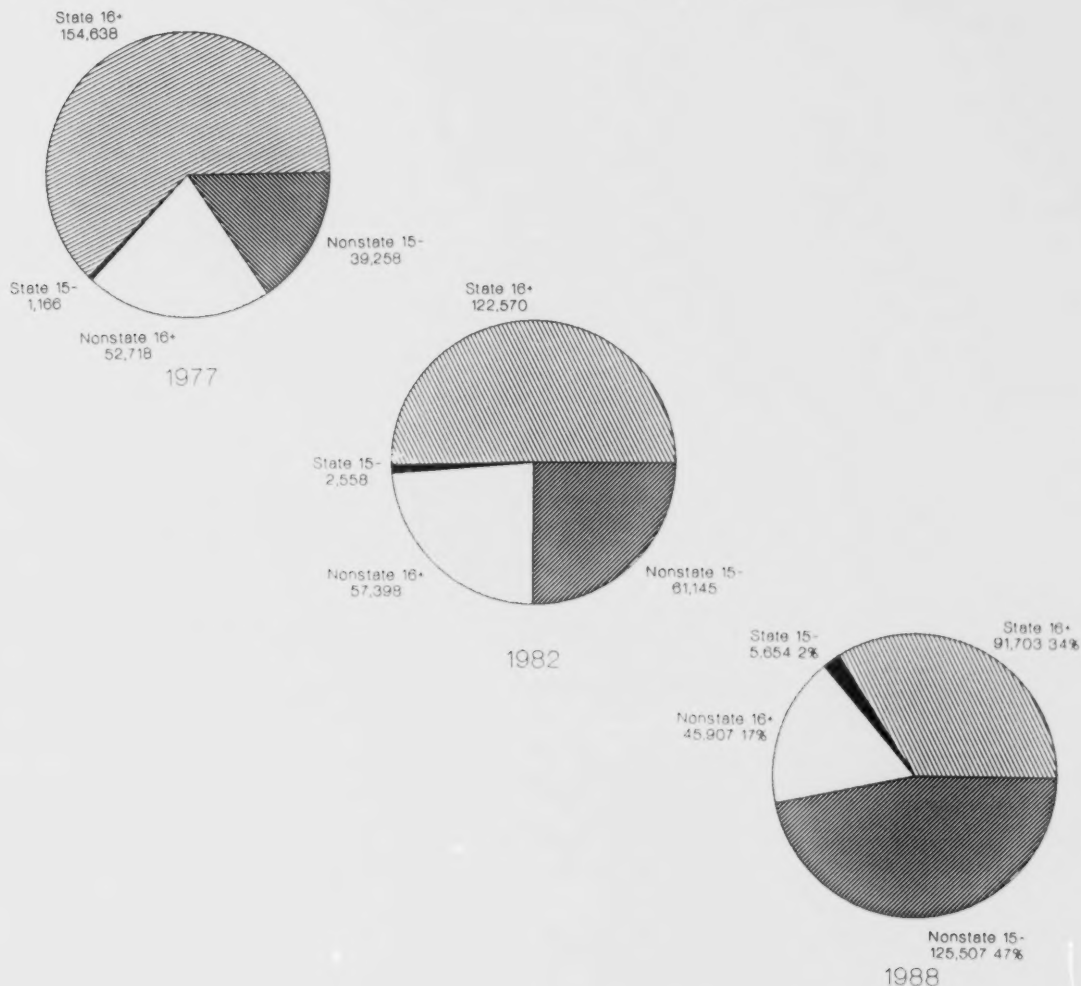
	1977	1982	1988
1-6	19,709	33,188	80,845
7-15	20,024	30,515	50,447
16-75	27,024	29,554	36,332*
76-299	37,298	42,775	39,568*
300+	143,040	107,637	61,709*

The actual or estimated number of residents in each of the size groupings of facilities in 1977, 1982 and 1988 are shown in this table.

* Estimates from the 1987 National Medical Expenditure Survey.

(Sources: Lakin, Hill, & Bruininks, 1985; Lakin, Hill, Chen, & Stephens, 1989; Lakin, White, Hill, Bruininks, & Wright, 1990)

Figure 1.7 Residents with MR/DD by Facility Size and Operator, 1977-1988



Although the number of persons living in residential facilities specifically for persons with MR/DD (that is, excluding nursing homes, psychiatric facilities and generic foster care homes) increased only about 8% from 1977 to 1988 (from approximately 247,800 in 1977 to 268,800 in 1988), there has been a notable decrease in the use of state-operated institutions, and an increase in the use of small, nonstate housing options. In 1977, approximately 62% of the persons with MR/DD in the residential services system were in state institutions; by 1988 that proportion had decreased to about 34%. In contrast, nonstate (private and locally operated) facilities expanded proportionately, from providing care to about 37% of the persons in the MR/DD residential care system in 1977 to providing care to 64% in 1988. There was also an increase in the number of persons served in the smaller state-operated facilities (15 or fewer residents), although these remained a small part of the entire residential care system nationwide (about 2% of all residents).

(Source: Lakin, White, Hill, Bruininks, & Wright, 1990)

Figure 1.8 Number of Residents in Large and Small Facilities by ICF-MR Certification

Since its enactment in 1971, the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program under Title XIX (Medicaid) of the Social Security Act has become the most significant source of federal support for residential services for persons with MR/DD. On June 30, 1988 more than 146,000 persons with MR/DD were living in ICFs-MR. These persons represented 54% of all persons nationwide who were living in residential facilities specifically licensed, contracted or operated by states to provide residential services to persons with MR/DD.

When the ICF-MR program was created, it was primarily focused on improving the conditions in large public institutions. Since then, as previous charts have shown, institutional placements have decreased substantially and have been replaced with much smaller community living arrangements. Although ICF-MR services may be offered in community residential facilities, critics of the program have suggested that largely due to the original institutional focus, the ICF-MR program today retains an "institutional bias" and that it 1) has created direct incentives for maintaining people in institutions by providing federal payment of from 50% to 80% of the costs of care in those facilities; 2) has diverted funds that could otherwise have been spent on more integrated, community-based programs into extremely costly institution renovations, primarily to meet ICF-MR facility standards; and 3) has established a single uniform standard of care that is insufficiently responsive to the needs and circumstances of individuals.

While the ICF-MR program continues to be primarily concentrated in institutions, there has been considerable shift over time to greater total and proportional inclusion of small facilities (15 or fewer residents). In 1977, only 4.2% (1,710) of the total 40,400 persons in small residential settings were in facilities certified as ICFs-MR. In 1982, 15.2% (9,714) of 63,700 persons in small residential facilities were in ICFs-MR. By 1988, the percentage of residents living in small residential facilities which were ICF-MR certified had increased to 22.1% (28,987) of a total 131,292 residents living in small facilities of 15 beds or less.

Not only has there been a large increase in the proportion of all small facility residents who are living in ICFs-MR, there has also been substantial increase in the proportion of all ICF-MR residents who are living in small ICFs-MR. In 1977, only 1.6% of all ICF-MR residents lived in facilities with 15 or fewer residents, while 98.4% lived in ICFs-MR of 16 or more residents. In 1982, 6.9% of all ICF-MR residents lived in facilities of 15 or fewer residents. In 1988, 19.8% of all ICF-MR residents lived in facilities of 15 or fewer residents, while 80.2% lived in ICFs-MR of 16 or more residents.

The number of residents of large facilities that are not ICF-MR certified has decreased rapidly over the past decade. In 1977 about 102,900 persons or nearly half of all residents of large facilities (16 or more residents) lived in places without ICF-MR certification, but by 1988 that number had decreased to 20,330, or only about 15% of the total of 122,504 large facility residents.

(Sources: Lakin, Hill, & Bruininks, 1985; Lakin, Prouty, White, Bruininks, & Hill, 1990)

Number of Residents in Large and Small Facilities by ICF-MR Certification

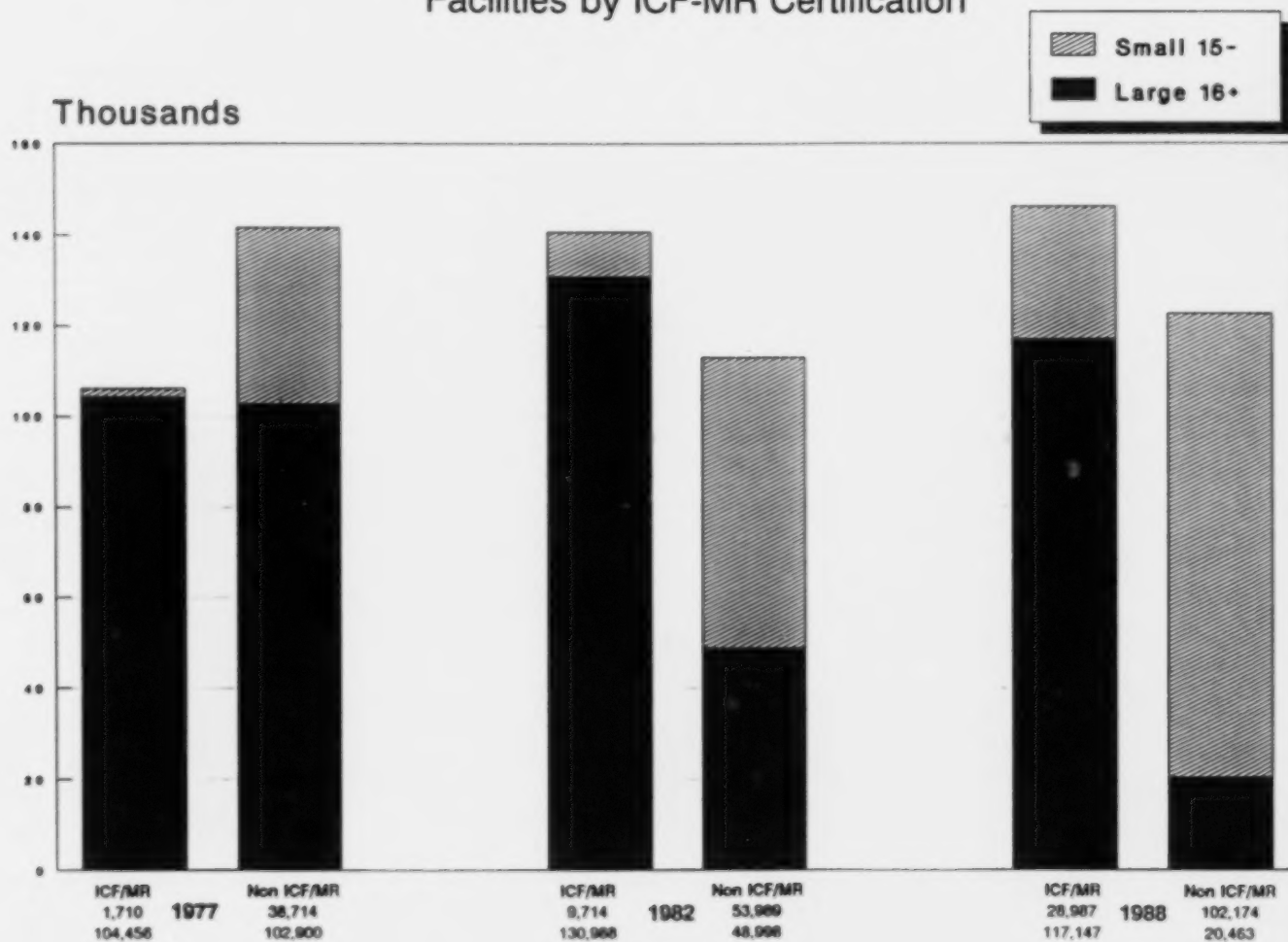


Figure 1.9 Living Arrangements of Youth with Developmental Disabilities

Only a small proportion of persons with developmental disabilities receive publicly-supported residential services. The vast majority live with their families or on their own. Children and youth with developmental disabilities are particularly likely to live with their parents and receive educational services from schools in their own communities, but even as they complete their school programs the majority continue to live with their families.

Information about the living arrangements of adolescents and young adults approaching and following the end of their schooling was gathered in the National Longitudinal Transition Study sponsored by the U.S. Department of Education. This study collected information about the living arrangements of students with handicaps in the last year of school, those out of school for less than a year, and those out of school for more than a year. This study estimated that the proportion of youth with developmental disabilities living with their families drops from about 95% while still in school to about 75% for those out of school more than a year. The most common residential arrangements for those out of school for more than a year were supervised living arrangements (an estimated 11% for persons with mental retardation and orthopedic handicaps, but 46% for persons labeled as multihandicapped). About 9% of students with mental retardation and orthopedic handicaps were living alone or with a roommate a year or more after completing school, as were only 3% of the students with multiple handicaps.

Current Living Arrangement	Mentally Retarded			Orthopedically Impaired			Multihandicapped		
	In-S	Out $\leq$ 1	Out > 1	In-S	Out $\leq$ 1	Out > 1	In-S	Out $\leq$ 1	Out > 1
Percentage of youth living:									
With parent(s)	93.0	79.3	75.7	93.4	95.0	76.8	86.0	70.5	50.2
Alone	0.0	0.4	1.7	0.3	1.8	1.6	0.0	0.5	0.9
With spouse/roommate	0.2	1.4	7.5	0.5	0.8	7.2	1.2	0.0	2.2
With other family member	2.6	8.3	3.5	3.7	0.6	1.2	1.5	5.6	0.6
In a residential/boarding school (not a college)	1.3	2.4	0.2	0.6	0.0	0.0	3.9	3.7	5.4
In a college dormitory	0.0	0.6	0.0	0.0	0.0	3.0	0.0	0.0	0.0
In military housing	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
In a supervised group home	2.6	3.5	3.1	1.2	1.8	0.8	6.1	7.3	5.4
In a mental health facility/hospital/institution for people with disabilities	0.0	2.4	8.2	0.2	0.0	8.1	0.5	6.4	34.8
In a correctional facility	0.5	1.3	0.0	0.0	0.0	0.0	2.0	0.0	0.0
Other	0.0	0.4	0.0	0.0	0.0	1.3	0.5	5.9	0.6
(Number of respondents)	562	202	183	438	104	118	438	93	109

(Source: Office of Special Education and Rehabilitation Services, 1989)

Figure 1.10 Number of Residents of Facilities for Persons with Mental Retardation and Related Conditions per 100,000 of State General Population in 1988

Figure 1.11 Percentage of Residents in Mental Retardation/Developmental Disabilities Facilities in Settings with 15 or Fewer Residents in 1988

Residents per 100,000 of state population. In 1988 states continued to vary remarkably in the total number of persons with mental retardation and related developmental disabilities in the various types and sizes of residential facilities for persons with MR/DD. Figure 1.10 shows states by the total number of people receiving residential services divided by the states' general populations (expressed in 100,000s).

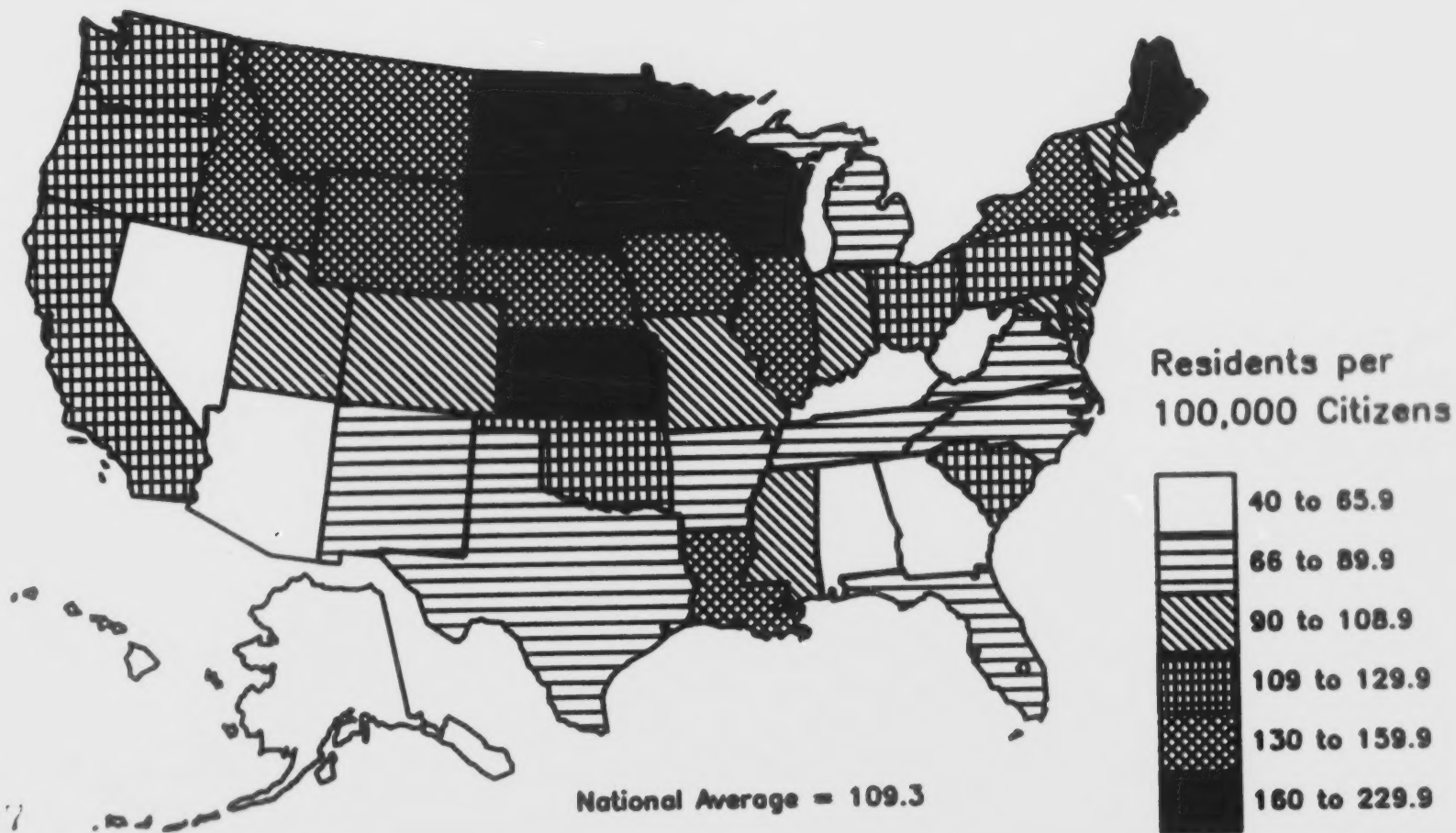
On June 30, 1988 states had an average total utilization of all residential placements for persons with MR/DD of 109.3 per 100,000 persons in the general population. States varied from 40.9 placements per 100,000 in Hawaii to 227.3 in North Dakota. Only four states had less than half the national placement rate--Alabama, Hawaii, Nevada and Kentucky. A majority of states (27) fell in the range of 73 to 145 placements per 100,000 in 1988. As a matter of historical comparison, in 1967, nationally there were 130.4 persons with MR/DD in residential care per 100,000 of the general population. In 1977 there were 118.8 persons with MR/DD in residential care per 100,000 of the general population. As will be shown in subsequent charts, the primary contributing factor to this decrease has been the large reduction of children and youth in residential care over the past two decades.

Percentage in settings of 15 or fewer residents. In 1988 states also varied widely in their utilization of smaller community-based residential settings (i.e., those with 15 or fewer residents). Nationally in 1988, 48.8% of all residents of public and private MR/DD facilities were living in places that had no more than 15 people living in them. States varied from lows of 14.2% in Mississippi, 19.3% in Texas, and 19.9% in Oklahoma, to highs of 82.5% in Arizona, 83.2% in Alaska, and 86.6% in New Hampshire. On June 30, 1988 a majority of states (28) had more than half their residential population residing in community-based facilities of no more than 15 residents.

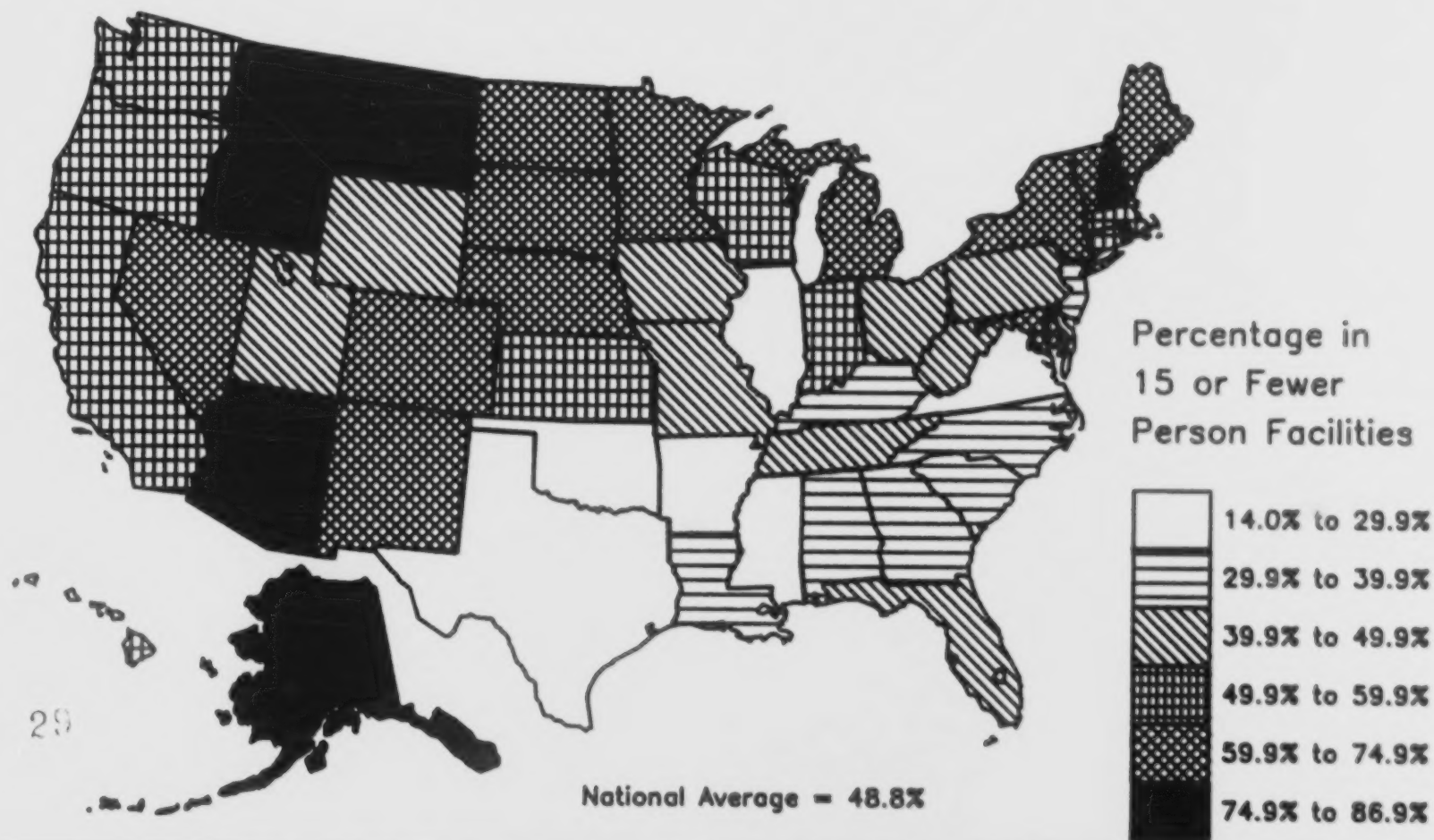
As an indication of national trends in the use of smaller facilities, in 1977 only 16.3% of all residents of public and private MR/DD facilities were living in places of 15 or fewer total residents. The proportion of all MR/DD facility residents in these smaller facilities increased to 26.1% in 1982, to 41.3% in 1986, to 46.4% in 1987, and to 48.8% in 1988. The 28 states with a majority of their MR/DD residential populations in facilities of 15 or fewer residents on June 30, 1988 represented an increase from 21 states on June 30, 1986.

(Sources: Lakin, Hill, & Bruininks, 1985; Lakin, Hill, White, & Wright, 1988; Lakin, White, Hill, Bruininks, & Wright, 1990)

Number of Residents of Facilities for Persons with Mental Retardation
and Related Conditions per 100,000 of State General Population in 1988



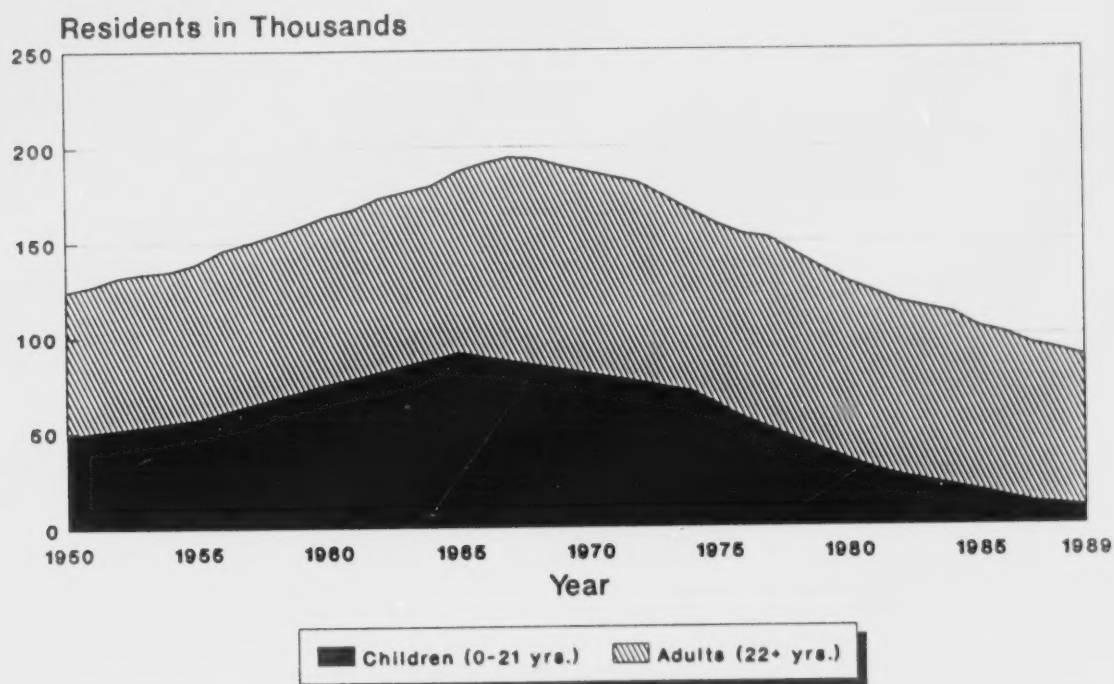
Percentage of Residents in Mental Retardation/Developmental Disabilities Facilities Living in Settings with 15 or Fewer Residents in 1988



PART II: What are the characteristics of people receiving residential services?

In recent years major shifts have occurred in the characteristics of the people living in different types of residential settings. A number of changing perceptions have contributed to and have resulted from those shifts, as community services have gradually replaced institutional care over the past quarter century. For example, initially community living was thought to be an appropriate alternative primarily for persons with mild or moderate degrees of impairment, who were among the first people to be transferred to community settings; that perception has been replaced by a growing recognition that, with proper support, persons with all degrees and types of impairment can experience and benefit from community living. Today, tens of thousands of persons with severe and profound mental retardation and associated physical, health and behavioral impairments live in community settings. From 1982 to 1988 the estimated number of people with profound mental retardation living in community facilities of 15 or fewer residents increased by over 150%, from about 6,000 to approximately 16,000. Other perceptions that have had a profound impact on the living arrangements for people with mental retardation and related developmental disabilities (MR/DD) have been more indirect. Probably the most notable of these has been acknowledgment of a basic public obligation to provide an appropriate education to all children and youth, including those with developmental disabilities. In addition, the importance of supporting and strengthening families to maintain their child at home has been recognized, and has become an alternative to providing costly and culturally atypical out-of-home residential care for children and youth. Such changing perceptions have been applied to all children, including those with the most severe impairments, and have contributed substantially to a 50% reduction in the number of children and youth with MR/DD receiving out-of-home residential services (from 91,000 in 1977 to 46,000 in 1988).

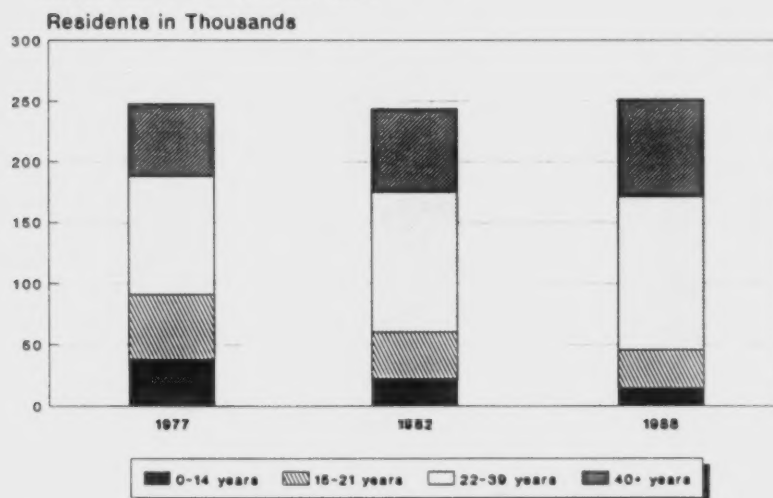
Figure 2.1 Total and Childhood (0-21 Years) Populations of State Mental Retardation Institutions, 1950-1989



This society has made a clear commitment in recent years to reduce the number of children and youth in out-of-home residential placement, especially placement in large state institutions. Simultaneously it has, through the creation of an educational entitlement for children with handicaps and other services for children and youth with MR/DD and their families, substantially reduced the demand for residential placements for children and youth. As a result of these initiatives, the number of children and youth in state institutions decreased by nearly 90%, from 91,592 in 1965 to 9,410 in 1989. In fact the number of children and youth in state institutions in 1989 was lower than the number of children and youth in state institutions in 1910 (10,547) when the total state institution population was only 19,499 persons of all ages. In 1965, children and youth 21 years or younger, made up nearly half (48.9%) of the 187,305 state institution residents; in 1989 children and youth made up only 10.7% of state institution residents. The decrease in children and youth has been much more rapid than the decrease in adult populations. In 1965 there were 95,713 adults (22 years or older) in state institutions; in 1989 there were 78,191. The largest population of institutionalized adults occurred in 1968 (109,022).

(Sources: Bruininks, Lakin, & Hill, 1986; Lakin, 1979; Scheerenberger, 1965, 1975, 1978, 1980, 1981, 1983, 1986, 1988, 1990)

Figure 2.2 Changing Age Distribution of Residents of MR/DD Facilities Providing Full-Time Supervision--1977, 1982, 1988



As a whole the population of residential care settings providing full-time supervision for persons with MR/DD (i.e., excluding semi-independent/supported living arrangements) has been getting older (see Figure 1.3 for specification of these MR/DD facilities). In part, this trend follows the general aging of the U.S. population, but has been occurring at a much more rapid rate. A number of other factors have accelerated this trend. At one end of the lifespan persons with MR/DD in residential facilities are much more likely to live to older ages than was once the case. But more importantly the average age at which persons first enter the residential care system has increased substantially, presumably because of educational entitlements and programs to assist families in raising their children at home. The number of children 0-14 years old receiving residential services in 1988 (14,735) was 39% of the 1977 total (38,161). The number of youth 15-21 years old in 1988 (31,012) was 59% of the 1977 total (52,781). The 1988 statistics are based on 1988 facility data, but use age estimates from the 1987 National Medical Expenditure Survey.

	1977		1982		1988	
	Number	% of Total	Number	% of Total	Number	% of Total
40+ year olds	59,470	24.0%	68,868	28.3%	80,097	31.8%
22-39 year olds	97,384	39.3%	114,410	46.9%	125,270	49.9%
15-21 year olds	52,781	21.3%	37,739	15.5%	31,012	12.3%
1-14 year olds	38,161	15.4%	22,652	9.3%	14,735	5.9%
TOTAL	247,796		243,669		251,125	

(Sources: Hauber, Bruininks, Hill, Lakin, & White, 1984; Lakin, Hill, & Bruininks, 1985; Lakin, Hill, Chen, & Stephens, 1989; Lakin, White, Hill, Bruininks, & Wright, 1990)

Figure 2.3 Ages of Persons with MR/DD in Residential Facilities of Different Sizes in 1987

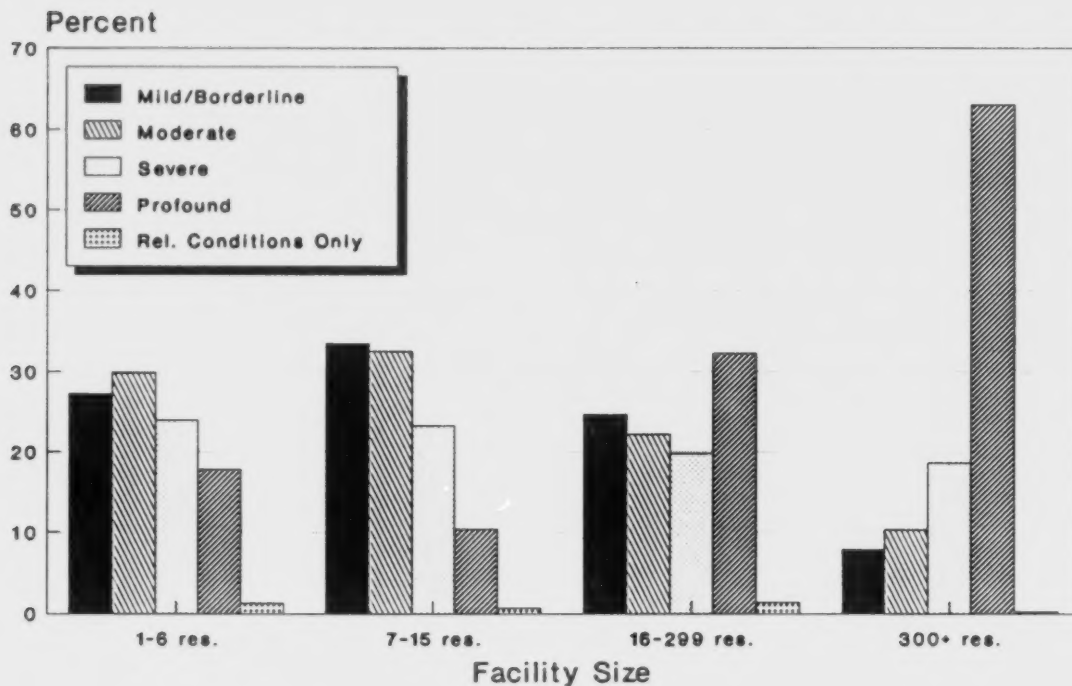


About half the population of residential facilities for persons with MR/DD is made up of people in early adulthood, 22-39 years, with a significant middle age population of 40-54 year olds. While an estimated 30.8% of the U.S. population was between 22 and 39 years in 1987, an estimated 51.6% of the population of MR/DD facilities was 22-39 years old. This age bulge to a large extent has resulted from the relatively low placement of children and youth in residential settings (only an estimated 15.5% of facility residents are 21 and younger), and relatively high numbers of people 65 years or older with MR/DD who have been placed in nursing homes.

Young adults (22-39 years) and middle aged adults (40-64 years) made up an estimated 79% of all residents in 1987. They predominated among the populations of all sizes of facilities. Children and youth were somewhat more likely to live in facilities of 1-6 residents and 16-299 residents, the latter including a number of residential schools, than in facilities of 7-15 residents or 300 or more residents. Persons over age 65 made up a fairly consistent 4% to 7% of the populations of the different sizes of facilities. Increasing life expectancy, efforts to reduce nursing home placement of people with MR/DD, and an estimated 20,000 current MR/DD facility residents in the 55-64 year age range, are all factors which suggest that the residential population of persons 65 years and older is likely to increase substantially by the end of this century.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 2.4 Persons with MR/DD in Residential Facilities by Facility Size and Level of Mental Retardation in 1987



There is a general association between the size of residential facilities and the diagnosed levels of mental retardation of their residents. Smaller facilities are likely to have more mildly handicapped individuals and larger facilities are more likely to have more severely handicapped individuals. In 1987, persons with mild/borderline mental retardation made up an estimated 27.2% of the population of facilities with 6 or fewer residents and 33.4% of the population of facilities with 7-15 bed residents, but only 7.9% of the population of facilities with 300 or more residents. In facilities with 1-6 residents, 17.8% of the residents were estimated to have profound mental retardation, as compared with 63% of residents in facilities with 300 or more residents. In the largest facilities, an estimated 81.6% of residents had severe or profound mental retardation, while 62% of persons in facilities of 15 or fewer residents had mild/moderate mental retardation. Still, significant numbers of people with severe and profound mental retardation live in the smallest settings--23.9% of the people living in facilities with 6 or fewer residents were reported to be severely mentally retarded, and 17.8% were reported to be profoundly mentally retarded.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 2.5 Behavior Problems among Residents of MR/DD Facilities of Different Sizes

Over the past 2 decades, the populations of large public institutions have been reduced by more than 50%, from about 195,000 persons with MR/DD in 1967 to about 88,000 in 1989. Most of the individuals discharged from public institutions over that period were placed in smaller (15 or fewer residents), community-based arrangements, which today house about 135,000 people with MR/DD. As this shift has happened, challenges that were once primarily reserved for institutional settings are now faced on a daily basis by staff of all types and sizes of residential facilities. Providing residential care to persons with behavior problems is one such major challenge. This challenge is particularly significant today as places are sought in smaller, community-based facilities for those persons with MR/DD who are still residing in larger institutions, many of whom have such behavior problems.

Over the years problem behavior has been statistically associated with initial admission and readmission to public institutions. In addition, it was a frequently cited barrier to certain kinds of community facilities (e.g., foster family care arrangements). However, as shown in Figure 2.5, today rather substantial proportions of people with MR/DD living in facilities of all sizes sometimes exhibit problem behavior. While the presence of problem behavior remains associated with larger institutional placements, clearly many people who exhibit problem behavior are living in smaller facilities. In fact, the recent growth in the number of persons in all sizes of community facilities who exhibit challenging behavior generally coincides with the growing number of persons who are living in such facilities who have other severe cognitive, medical and/or functional impairments. For instance, as the number of people with severe and profound mental retardation living in community facilities increases, the higher prevalence of self-injury among persons with severe or profound mental retardation (30% vs. 13% for persons with mild mental retardation) contributes to increased prevalence of self-injury in smaller, community-based residential facilities.

Overall, in the 1987 National Medical Expenditure Survey an estimated 28.5% of people with MR/DD in mental retardation facilities were reported to sometimes attempt to hurt others physically. Large facilities (16 or more residents) reported rates that were only slightly higher than small facilities (29.9% compared to 25.2%). An estimated 22.4% of residents were reported "sometimes" to try to hurt themselves. Differences between large and small facilities were relatively small (23.6% compared to 19.4%). An estimated 15.7% of residents were reported to steal from others on occasion, with consistent rates across the different facility sizes. An estimated 12.4% of residents were reported to expose themselves or to exhibit other problem sexual behavior, with similar rates across the different facility sizes.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Behavior Problems Among Residents of MR/DD Facilities of Different Sizes

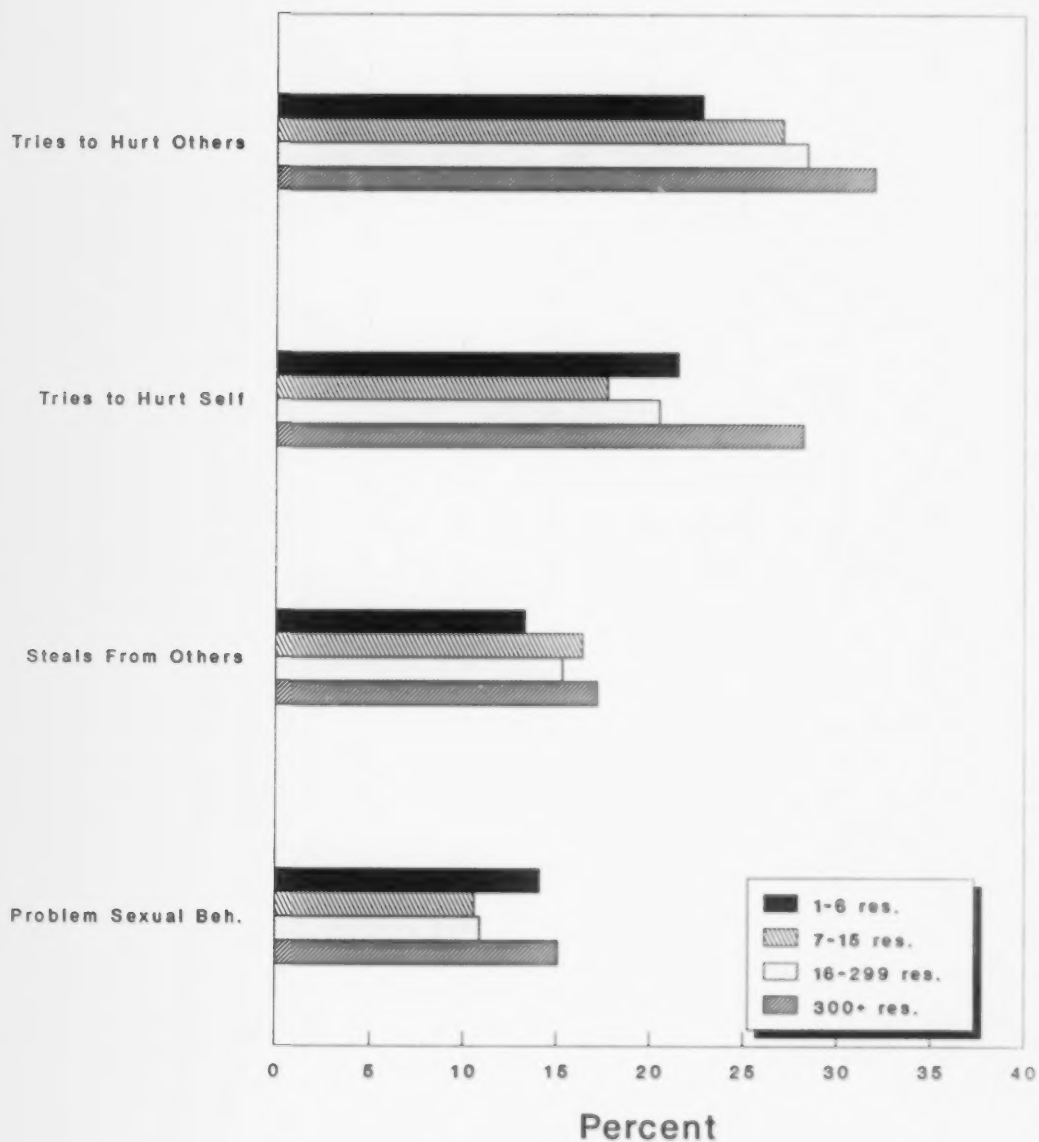


Figure 2.6 Prevalence of Related Conditions among Residents of MR/DD Facilities in 1987

A number of conditions in addition to mental retardation are prevalent among residents of mental retardation facilities. Among these are: epilepsy, cerebral palsy, autism, spina bifida, deafness and blindness. With the exception of autism and spina bifida these conditions were more commonly found among the population of facilities with 16 or more residents than among people living in smaller facilities.

Epilepsy. An estimated 29.6% of persons with mental retardation and related developmental disabilities in residential settings were reported to have epilepsy. Prevalence varied among facilities of different sizes. An estimated 33.8% of residents in facilities with 16 or more people have epilepsy, including 40.5% of residents in facilities of 300 or more residents. Among the smaller facilities, a larger proportion of residents in the smallest homes (1-6) were reported to have epilepsy (22.8%), than in the 7-15 person facilities (17.1%).

Cerebral Palsy. An estimated 11.7% of persons with MR/DD in residential settings were reported to have cerebral palsy. The estimated prevalence was 13.2% in facilities of 16 or more residents and 8.2% in smaller facilities. There were no differences between facilities of 6 and fewer residents and 7-15 residents in the estimated prevalence of cerebral palsy.

Autism. The estimated prevalence of autism among residents of MR/DD facilities was 3.5%. Estimates were similar for larger facilities with 16 and more residents (3.7%) and smaller facilities (3.0%). However, autism was more commonly reported among people living in settings with 6 or fewer residents (4.3%) than among people living in facilities with 7-15 residents (2.1%).

Spina bifida was estimated to be rare among persons living in MR/DD facilities (0.5%), with no statistically significant differences by facility size.

Deafness or blindness. An estimated 7.2% of the residents of MR/DD facilities were either blind or deaf or both. This included 8.7% of the people living in facilities of 16 or more residents and 10.7% of the population of facilities with 300 or more residents. In comparison 3.7% of the persons living in facilities of 15 or fewer residents were reported to be blind or deaf or both. The estimated proportion of the population of people with deafness or blindness steadily increases with the size of the facility: 3.0% for facilities with 6 or fewer residents, 4.2% for facilities with 7-15 residents, 6.4% for facilities with 16-75 residents, 7.4% for facilities with 76-299 residents, 10.2% for facilities with 300-799 residents and 12.8% for facilities with 800 or more residents.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Prevalence of Related Conditions Among Residents of MR/DD Facilities in 1987

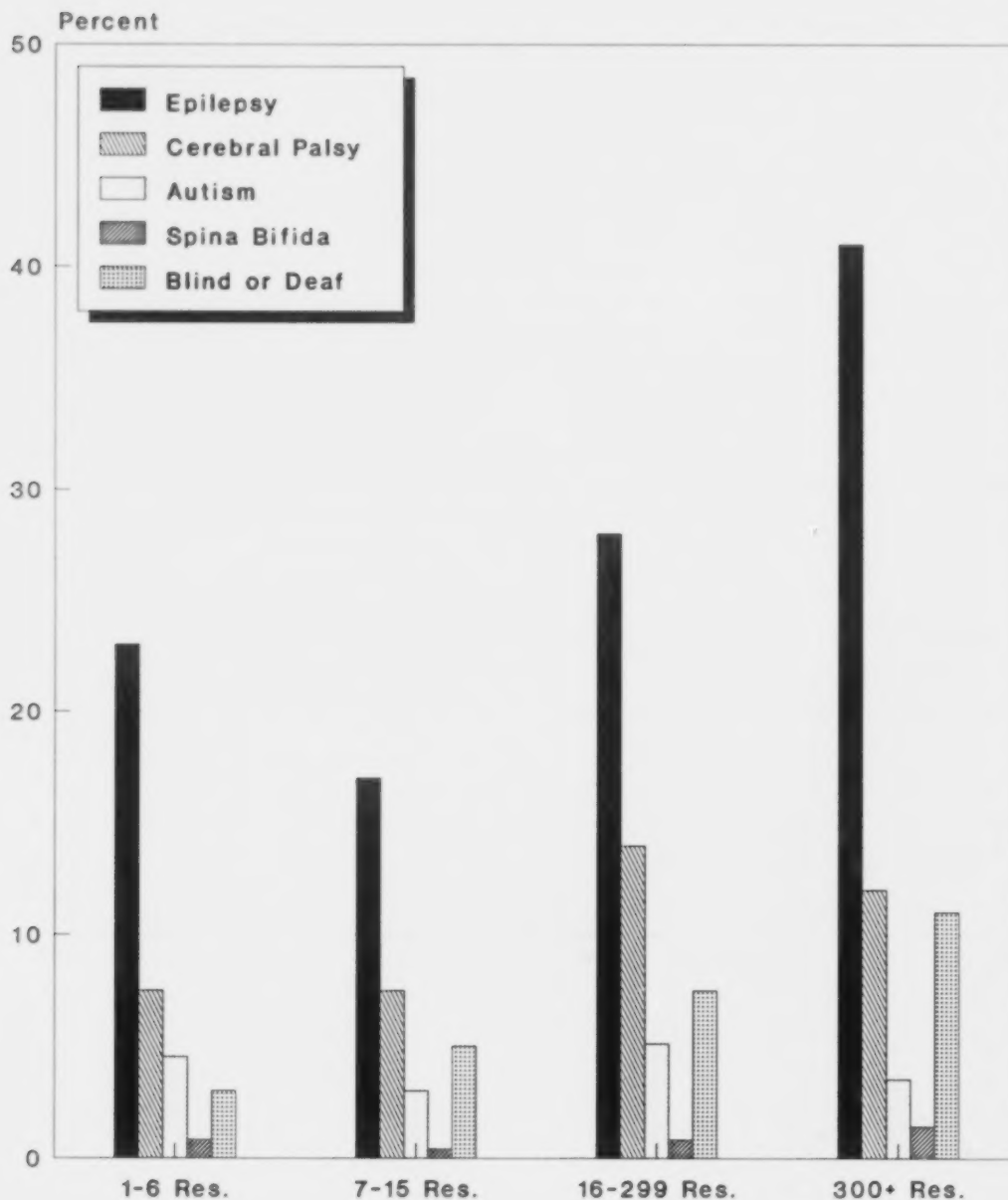


Figure 2.7 Independent Performance of Activities of Daily Living by Residents of MR/DD Facilities of Different Sizes in 1987

Generally the smaller the settings in which people live the more likely they are to be reported as independent in important activities of daily living. The single exception to this rule in the data gathered in the 1987 National Medical Expenditure Survey was that residents of facilities with 7 to 15 residents were somewhat more likely to be reported to be independent in activities of daily living than residents of facilities with 6 or fewer residents. But even a majority of residents of the largest facilities were reported to be independent in basic activities such as feeding themselves, walking across a room, using the toilet, and getting in and out of bed. The activities in which residents were least likely to have attained independence were bathing/showering and dressing. This was true for all sizes of facilities.

Bathing/Showering. An estimated 39.1% of residents of MR/DD facilities were reported to be able to bathe or shower independently, including 31.5% of residents of small facilities (15 or fewer residents) and 57.0% of residents of large facilities (16 or more residents). Only 22.4% of residents of facilities with 300 or more residents were reported to be independent in bathing or showering.

Toileting. An estimated two-thirds (68.1%) of residents of MR/DD facilities were reported to be able to use the toilet independently. Independent toilet use was reported for 86% of small facility residents and 60.4% of residents of large facilities.

Getting in and out of bed. An estimated 80.3% of residents with mental retardation and related conditions were reported to be able to get in and out of bed independently, including 94% of small facility residents and 74.4% of large facility residents. Only an estimated 52.4% of persons in facilities with 300 or more residents were reported to be able to get into and out of bed independently.

Feeding self. An estimated 77.2% of all residents were reported to be able to feed themselves without assistance, including 90.7% of small facility residents and 71.5% of large facility residents. An estimated 65.7% of persons living in facilities with 300 or more residents were reported to be able to feed themselves independently.

Walking across room. An estimated 77.3% of residents of MR/DD facilities were reported to be able to walk across a room independently without physical assistance from other people or with the use of equipment. This included 91.2% of small facility residents and 77.3% of large facility residents. The proportion of residents who were reported to be unable to walk across a room even with the assistance of another person or of equipment was 2.9% in small facilities and 17.5% in large facilities.

Dressing. An estimated 45.6% of the persons living in MR/DD facilities were reported to be independent in dressing themselves, including 62.6% of small facility residents and 38.4% of large facility residents. An estimated 26.9% of the persons living in facilities of 300 or more residents were reported to be independent in dressing themselves.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Independent Performance of Activities of Daily Living by Residents of MR/DD Facilities of Different Sizes in 1987

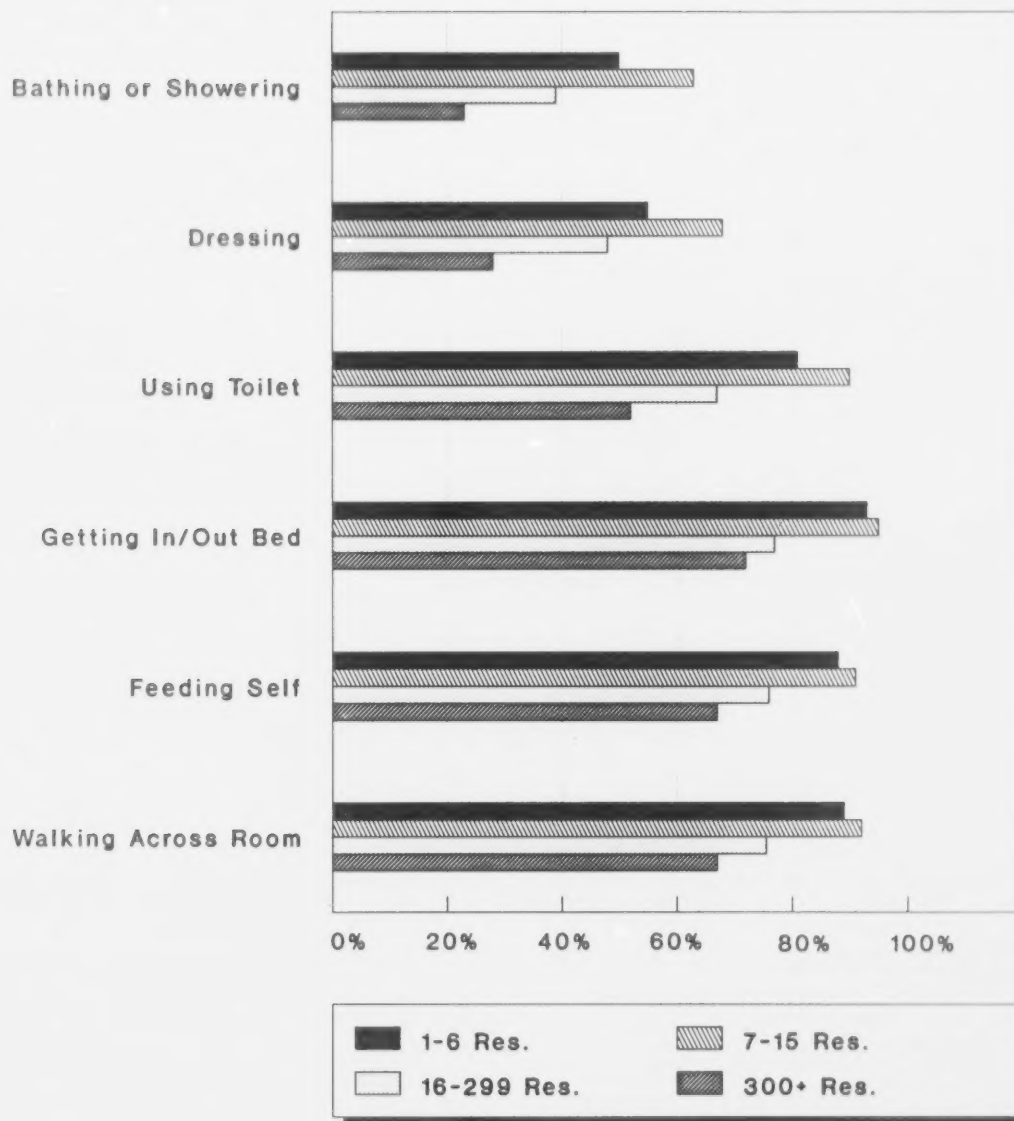
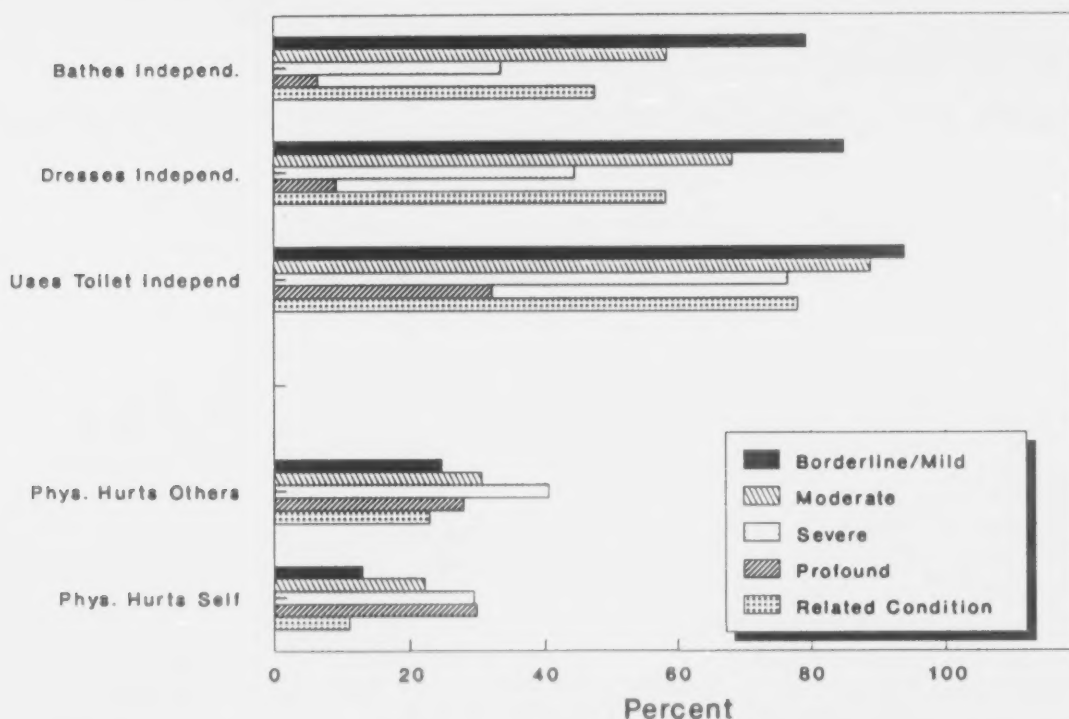


Figure 2.8 Selected Characteristics of Persons in MR/DD Facilities by Level of Retardation or Related Conditions

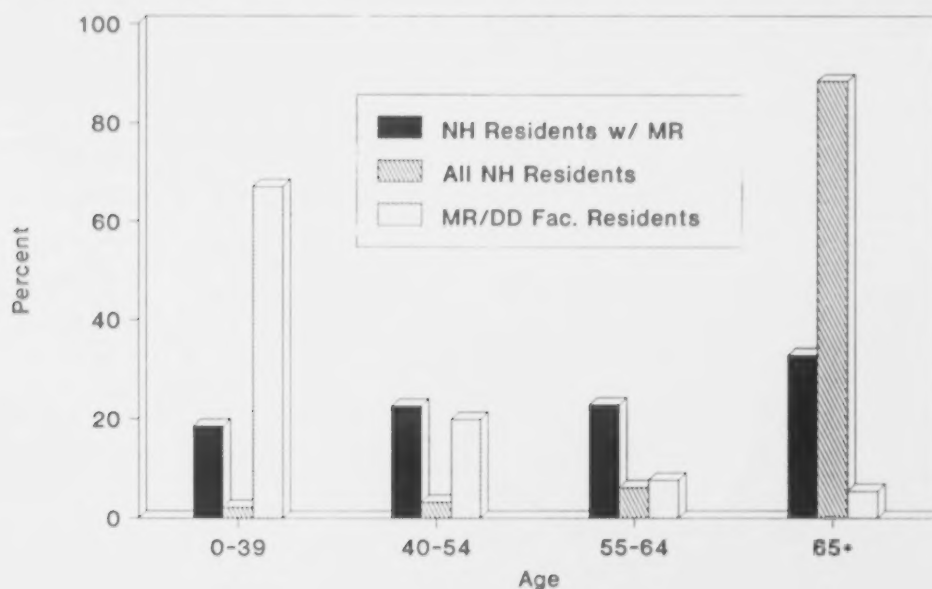


Reported independent performance of selected activities of daily living shows clear and expected associations with level of mental retardation. In the 1987 National Medical Expenditure Survey the proportion of residents reported to be independent in performance of three selected activities of daily living decreased steadily with the level of cognitive impairment. Among persons with profound mental retardation, independence was much less frequently reported than among individuals with severe mental retardation. For persons with related conditions who were not mentally retarded, the proportion of residents reported to be independent was in a range between the levels reported for persons with moderate and severe retardation.

The prevalence of two selected problem behaviors, hurting others and hurting self, was much less associated with level of mental retardation than were the activities of daily living. The prevalence of aggressive behavior toward others was reported to be highest among persons with severe mental retardation (40.6%), with fairly consistent rates (between 24.7% and 30.6%) for other groups. Reported prevalence of self-injurious behavior was highest among persons with severe and profound mental retardation (29.4% and 29.8%) and lowest among persons with mild/borderline mental retardation and persons who have related conditions but not mental retardation (13.0% and 11.0%).

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 2.9 **Ages of Persons with Mental Retardation in Nursing Homes in 1985**

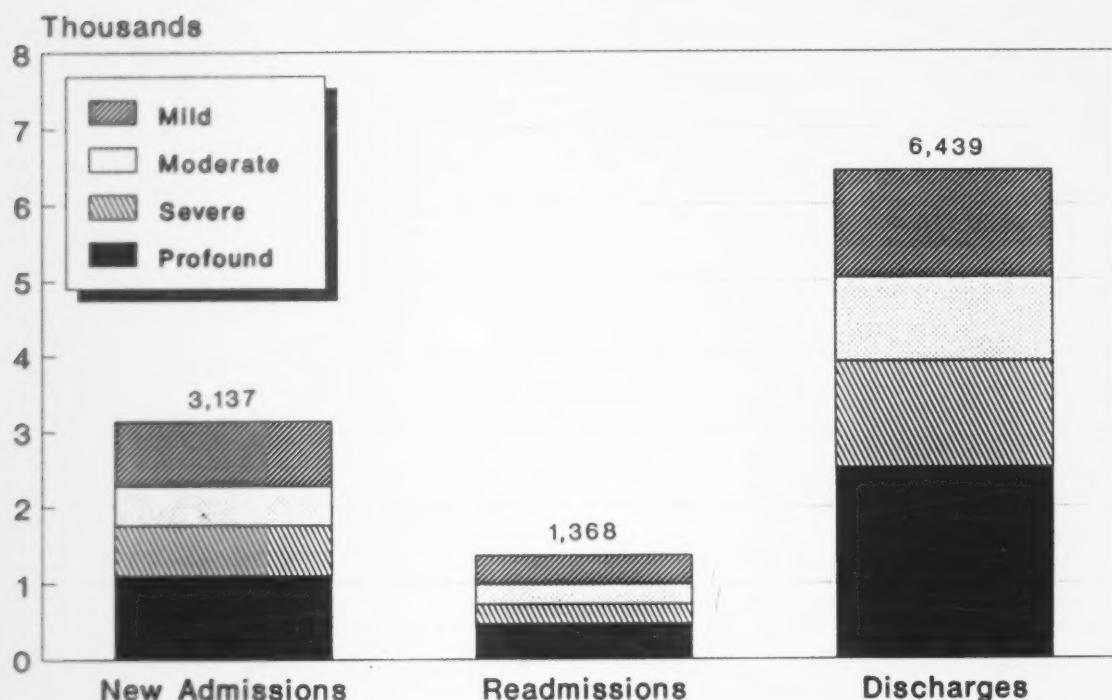


In addition to persons who reside in facilities primarily for people with mental retardation and related developmental disabilities, a large number of people with MR/DD live in nursing homes. Many of these individuals are placed in nursing homes primarily because of mental retardation and associated care needs rather than because of specific medical or nursing needs. The estimates of 40,538 nursing home residents with a primary diagnosis of mental retardation in nursing homes in 1985 are from the 1985 National Nursing Home Survey. The 1987 National Medical Expenditure Survey yielded an estimate of 45,261 for the same population. Studies gathering individual state estimates for 1988 obtained estimates of 42,700 (Lakin et al., 1990) and 50,600 (Braddock et al., 1990). As shown in Figure 2.9 nursing home residents with mental retardation tend to be much older than persons in MR/DD facilities and much younger than other residents of nursing homes.

Age	Nursing Home Residents with Mental Retardation		All Nursing Home Residents		MR/DD Facility Residents in 1987	
	Est.	%	Est.	%	Est.	%
0-39 years	7,478	18.4%	32,141	2.2%	171,321	67.0%
40-54 years	10,374	25.6%	48,768	3.3%	50,629	19.8%
55-64 years	9,740	24.0%	91,819	6.2%	19,689	7.7%
65+ years	12,946	31.9%	1,318,672	88.4%	14,064	5.5%
TOTAL	40,538		1,491,400		255,703	

(Sources: Lakin, Hill, & Anderson, 1989; Lakin, Hill, Chen, & Stephens, 1989)

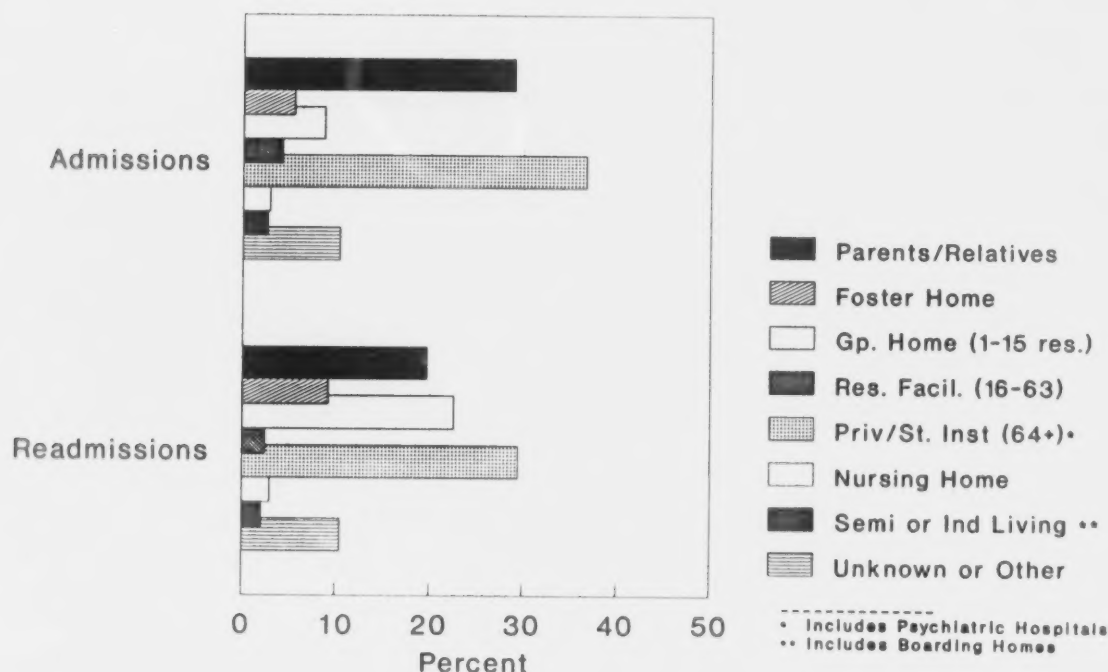
Figure 2.10 Admissions and Discharges from State Institutions by Level of Retardation in 1989



The number and characteristics of persons released from, admitted and readmitted to (and dying in) state institutions determines the changes in the size and characteristics of the population during the year. A total of 6,439 persons were discharged from large state institutions in 1989. However, admissions to state institutions, including 3,137 persons who were newly admitted and 1,368 persons who were readmitted, replaced 70% of the total number of people who were discharged. A total of 1,333 deaths were also reported in 1989. The proportions of persons newly admitted, readmitted, and discharged were generally similar among residents with different levels of mental retardation, although persons with mild mental retardation made up a higher proportion of those admitted than discharged and persons with profound mental retardation were somewhat more likely to be discharged than admitted. Although persons with profound mental retardation made up 39% of all discharges, this was considerably less than their proportion in the total state institution population (63%).

(Source: Scheerenberger, 1990)

Figure 2.11 Previous Placement of Persons Admitted or Readmitted to Large State Residential Facilities in 1989



Statistics on persons admitted or readmitted to large state institutions provide important indicators of the success of community and family-based services. In FY 1989 the admission rate to state institutions (both admissions and readmissions) was 5.1 admissions per 100 average daily residents in 1989. This was a decrease from 6.4 in 1985 and 5.9 in 1987. Most new admissions came from family settings (34.5%), either the home of their parents or another family member (29.0%) or a foster home (34.5%), or from other institutions with 16 or more residents (46.7%), including MR/DD institutions (25.4%), nursing homes (2.7%), psychiatric facilities (15.5%), and correction facilities (3.1%). In FY 1989 most persons readmitted to state institutions had been living in community settings, including a family member's home (19.7%), a foster home (9.2%) or small group homes, boarding homes or semi-independent living arrangements (24.0%). A sizable proportion of the readmissions were people returning to a state institution in which they had once lived from another institution (35.9% of readmissions came from other types of institutional settings). While any readmission from community and family living arrangements should raise concern about the effectiveness of community services and supports, the FY 1989 readmission rate of 1.7 readmissions per 100 average daily residents did compare favorably to the rate of 2.0 in 1985 and 1987, and the rate of 1.9 in 1982.

(Sources: Scheerenberger, 1983, 1986, 1988, 1990)

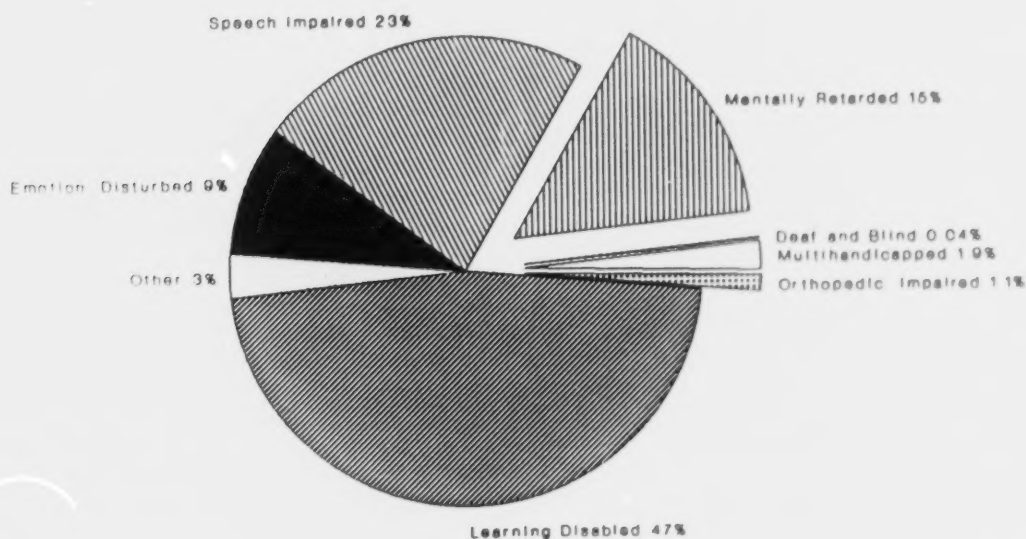
PART III: Where are children and youth educated?

In the 1987-88 school year 4,127,568 children and youth ages 6 to 21 received special education in programs funded in part under the Education of All Handicapped Children Act (P.L. 94-142), and Chapter 1, Handicapped Programs of the Education Consolidation and Improvement Act--State Operated Programs. Another 337,000 three to five year olds and 30,000 infants and toddlers (0-2) received services under one of these laws. The total of 4,494,280 children and youth served was 1.6% more than the total served in 1986-87. The number of children and youth who receive special education and related services has grown every year since 1976, with an overall increase of 21.2 percent since 1976-77. Programs for infants, toddlers, and preschoolers have been a major contributor to the increases in the last two years.

Two of the initial and most basic goals of the Education for All Handicapped Children Act were to provide an appropriate education to students with the most severe impairments, many of whom were denied an education prior to enactment of the Act, and to increase educational integration of students with handicaps. More recently, goals have been established to improve services both before and after the traditional years of schooling. In 1986, the Handicapped Infants and Toddlers Program (P.L. 99-437) was established; all fifty states currently participate. For secondary and post-secondary age students, who face the challenging transition to adult life, extended educational programs are being implemented, with special training to improve preparation for employment, more independent living and other areas of adult life.

The following set of charts on special education services utilizes statistics drawn from the U.S. Department of Education's state reporting system and the categorical disability groupings of that system. Students considered to be developmentally disabled in these charts are ones diagnosed as having mental retardation, multiple handicaps, orthopedic/physical handicaps, or deafness and blindness.

Figure 3.1 Percentage of Students (6-21) Receiving Special Education Services by Handicapping Condition, School Year 1987-88

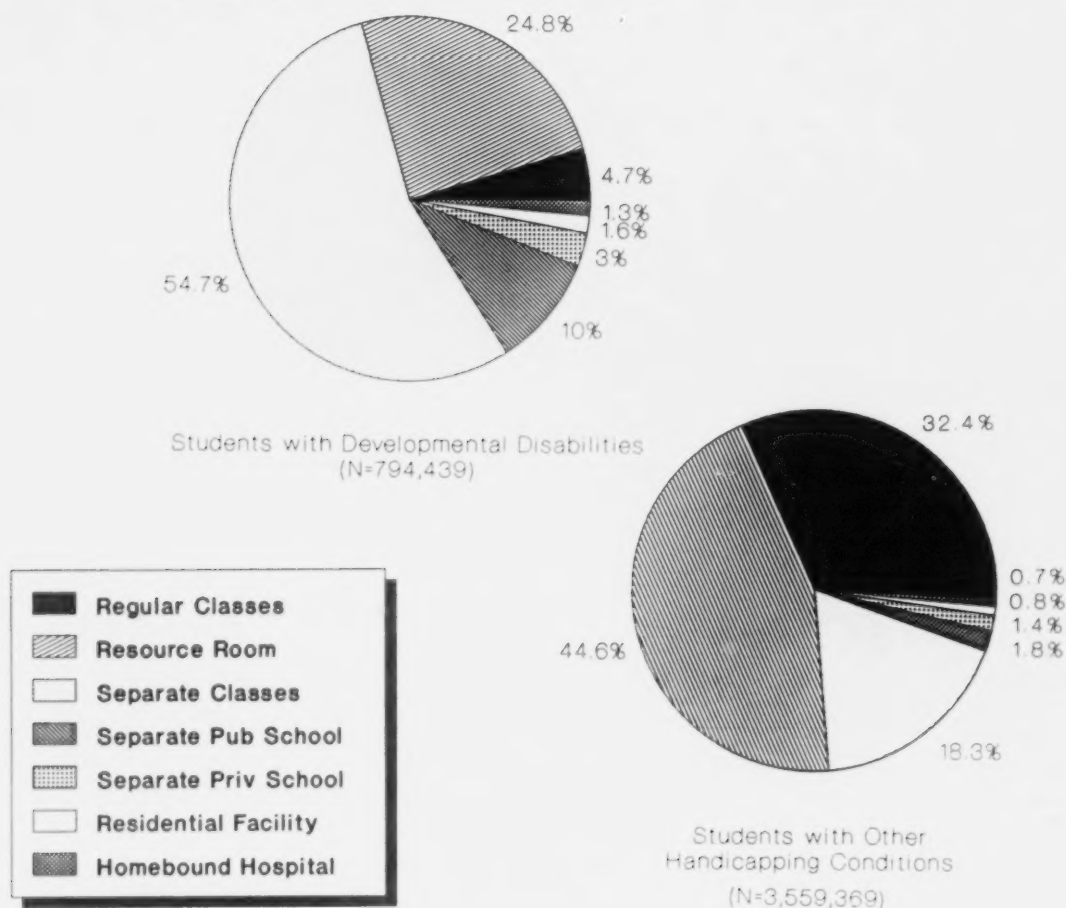


The four most frequently reported handicapping conditions for special education students in the 1988 school year were learning disabilities, speech impairment, mental retardation, and emotional disturbance. Together these four conditions accounted for 94% of students served in special education programs. Students categorically defined as having developmental disabilities made up 17.7% of students with handicaps. Students with mental retardation made up 14.6% of special education students. Children and youth with multiple handicaps made up 1.9% of all special education students. Students with orthopedic handicaps and with both deafness and blindness made up 1.1% and .04% of special education students, respectively.

The number of students with mental retardation decreased by 3% between the 1986-87 school year and the 1987-88 school year, presumably because of continued preferences for the "learning disabilities" label over the "mentally retarded" label. During the same period, students with learning disabilities increased by 2%. Students classified as multihandicapped increased by 2.8%, orthopedically impaired by 4.7% and deaf-blind by 5.4%.

(Source: Office of Special Education and Rehabilitation Services, 1989)

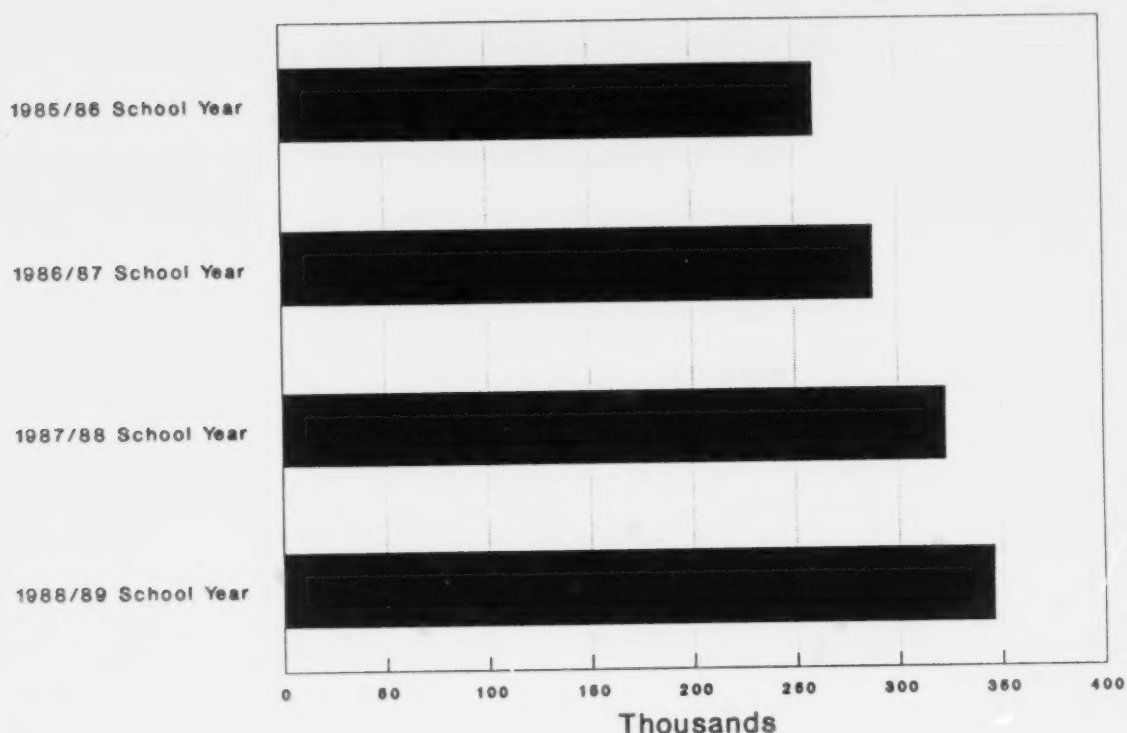
Figure 3.2 Educational Placements of Students with Developmental Disabilities in the 1986-87 School Year



In the 1986-1987 school year the vast majority of the 794,000 students with developmental disabilities received their education away from their non-handicapped peers. Only 5% participated in full-time regular classroom placement, while 55% received special education and related services in separate classrooms, 10% in separate public schools, 3% in separate private schools, 2% in residential schools, and 1% in home-bound or hospital programs. One quarter of students with developmental disabilities participated in resource room programs. Students with developmental disabilities were much more likely to be in separate programs than other students with handicaps. For example, in 1987, 32% of students with handicaps other than developmental disabilities were educated in regular classes as compared with 5% of students with developmental disabilities. About 18% of students with handicaps other than developmental disabilities were educated in separate classrooms as compared with 55% of students with developmental disabilities.

(Source: Office of Special Education and Rehabilitation Services, 1989)

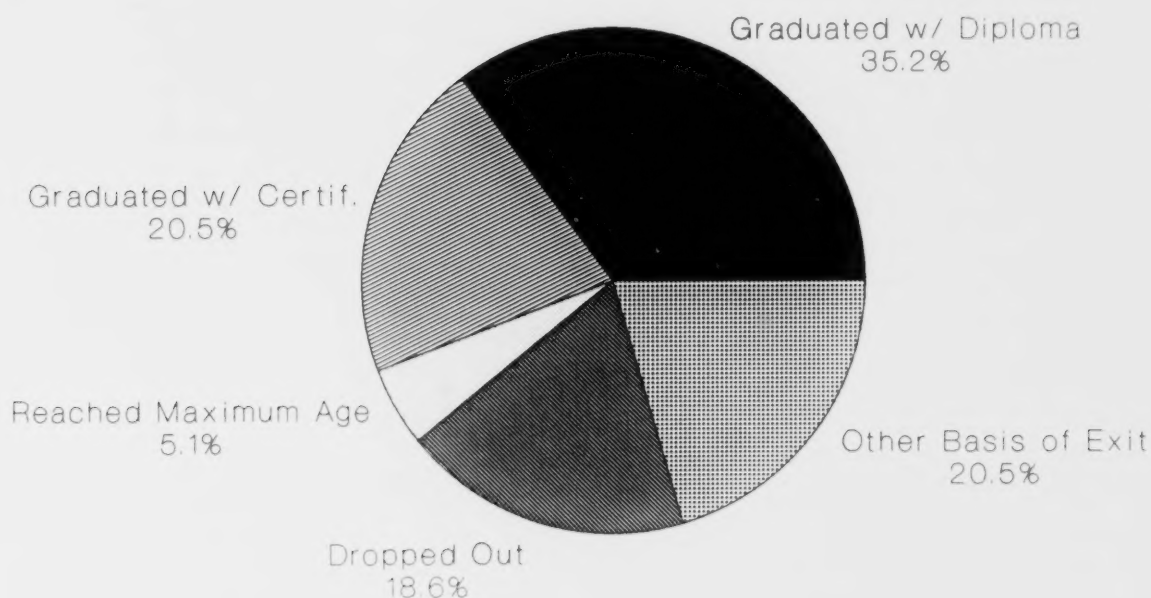
Figure 3.3 **Estimated Number of Children, Ages 3-5, Receiving Early Intervention Services**



Early intervention is increasingly recognized for its importance in limiting the long-term impact of developmental disabilities. The actual numbers of preschool children receiving early intervention services is difficult to determine, because reporting systems often differ from school-age systems, and duplicate and incomplete counts sometimes result from the numerous diverse agencies providing such services. However, between the 1985-1986 and 1988-1989 school years states reported rapidly growing numbers of 3 to 5 year olds receiving early intervention services, from 260,000 in 1986, to 288,301 in 1987, to 323,119 in 1988, and to 346,119 in 1989.

(Source: National Early Childhood Technical Assistance System, 1990)

Figure 3.4: Basis of Exit of 16-21 Year Olds with Developmental Disabilities Leaving the Educational System during the 1986-1987 School Year



The majority of special education students with developmental disabilities in the 16-21 year age range who left school in the 1986-1987 school year did so as high school "graduates"--either with a diploma (35.2%) or a certificate (20.5%). This graduation rate compares to 46% of all special education students who received a diploma, and 13% who received a certificate. These rates compared with an overall 71% graduation rate for nonhandicapped students.

The dropout rate for students with developmental disabilities was 18.6%. This was lower than the rate of 25% for all special education students and at the high end of the estimated rate of 14% to 18% for nondisabled students. About 5.1% of students with developmental disabilities left school without graduating when they had reached the maximum age for educational services ("aging out"). This was higher than the rate of 3% reported for all special education students.

(Source: Office of Special Education and Rehabilitation Services, 1989)

PART IV: Where do people work?

It is typical in our culture that once out of school, adults work and contribute to society. In recent decades, and particularly *in the last one*, there has been growing emphasis on employing persons with developmental disabilities and on paying them appropriately for their work. With greater commitment to more normal lifestyles for all persons with developmental disabilities, better understanding of their abilities, and growing knowledge of how to assist people in productive activities, the considerable recent increase in real jobs with real pay is likely to continue.

A number of different service models have been developed to provide training and on-going support to enable persons with developmental disabilities to contribute to society through work:

Sheltered Employment. Work environments in which only persons with disabilities are employed; payment is customarily at less than minimum wage, often piece rate.

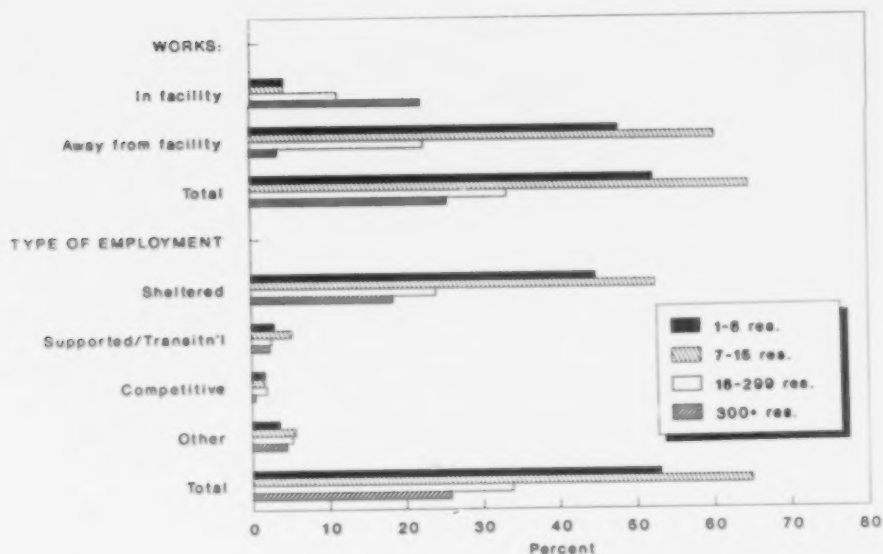
Transitional Training/Employment. Employment providing time-limited support leading to competitive employment; may include work/employment training stations, on-the-job training or enclaves (a number of persons with disabilities in a special unit within a competitive workplace).

Supported Employment. Employment which requires ongoing support, in work environments where persons without disabilities are employed; payment is often less than minimum wage.

Competitive Employment. Unsubsidized employment in environments in which persons without disabilities are employed; may include certain enclaves, work crews, and regular jobs with time-limited, follow-along services; payment is at or above minimum wage.

This section describes the recent and current status of the employment of persons with mental retardation and related developmental disabilities. Information from four different national studies reflects the great variety of initiatives currently underway in this area, and the enormous amount of work still needed. Statistics presented in the following pages indicate that, although employment efforts are increasing, only a small minority of persons with developmental disabilities are afforded supported or competitive work opportunities and those who receive them seldom include persons with severe impairments.

Figure 4.1 Employment of Adults Living in MR/DD Facilities in 1987



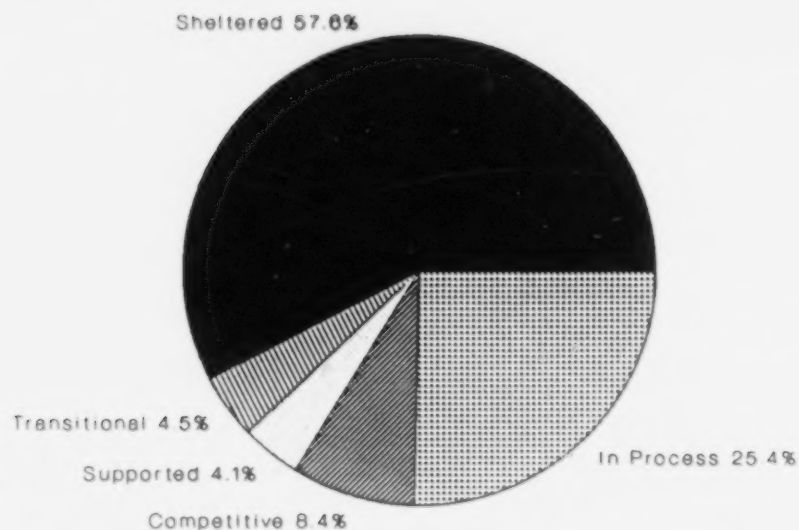
An estimated 39% of all persons living in MR/DD facilities were employed for pay in 1987. There were substantial differences between residents of large (16 or more residents) and small facilities. It was estimated that 52.4% of people living with 6 or fewer other people, worked for pay, as did 64.7% of residents living with 7-15 other people. In the large facilities, 22.6% of residents of facilities with 16-299 residents worked for pay, as did 25.6% of the people living in the facilities with 300 or more residents.

Location of Employment. A significantly greater proportion of residents in small facilities worked away from the facility than residents of large facilities. In facilities with 6 or fewer residents, 48% worked away from the facility, as did 60.4% of people living in places with 7-15 residents. In facilities with 16-299 residents, 22.6% of the residents worked outside the facility, as did only 3.6% of residents facilities with 300 or more residents.

Type of Employment. An estimated 29.8% of all people with MR/DD in mental retardation facilities worked in sheltered workshops. Sheltered workshop employees made up 76.8% of all residents working for pay. An estimated 44.8% of persons in facilities of 6 or fewer residents were in sheltered employment (84% of employed residents), as were 52.5% of residents of 7-15 person facilities (81% of all those employed). Only 24% of residents of 16-299 person facilities were in sheltered employment (71% of all employed), as were 18.5% of residents in facilities with 300 or more residents (72% of all employed). Only 3% of all residents were in supported/transitional employment, 1.4% were in competitive employment, and 4.8% were in "other" (primarily "in-facility") employment.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 4.2 **Percent of Adults with Developmental Disabilities Served in Various Types of Employment Settings in 1986**



In 1987, the Developmental Evaluation Clinic, a University Affiliated Facility at Boston Children's Hospital, studied the placement activities of approximately 1000 vocational rehabilitation agencies, organizations and facilities providing vocational services to adults with developmental disabilities across the country. It found that of the 96,626 persons served during the 1985-86 period, 57.6% were served in sheltered employment. A total of 17% were placed into nonsheltered employment, 8.4% into competitive employment, 4.1% into supported employment, and 4.5% into transitional training employment programs. At the time of the survey, the remaining 25.4% were reported to be "in process" between placements.

(Source: Kiernan, McGaughey, Schalock, & Rowland, 1988)

Figure 4.3 Growth in the Number of Supported Employment Workers in 20 States, 1986-1988

Supported employment initiatives of the federal government have assisted many states and agencies in developing supported employment programs. Major system change model demonstration grants were made in 1985 and 1986 to 27 states by the Office of Special Education and Rehabilitative Services. The purpose of these awards was to modify or convert the existing adult services systems of segregated day programs to industry-based paid employment, with a major focus on persons with severe disabilities.

A total of 20 states have participated in the projects since 1985 and have been able to report participants for fiscal years 1986, 1987 and 1988. In this three-year period, the total number of individuals in supported employment in these states grew by almost 250%, from about 9600 in FY 86 to about 22,800 in FY 88. The statistics reported here represent the total number of individuals in all supported employment programs in the state known to the state project director.

The states and their actual figures are:

	FY 86	FY 87	FY 88
Alaska	45	96	142
California	812	1,803	3,276
Colorado	323	909	1,073
Connecticut	763	1,467	2,658
Delaware	22	106	170
Florida	0	232	721
Kansas	0	64	130
Kentucky	51	197	286
Maryland	627	976	1,035
Minnesota	3,047	4,425	4,587
Montana	70	98	156
New Hampshire	100	300	705
New York	612	1,000	2,350
Oregon	147	147	642
Pennsylvania	0	89	245
Utah	0	62	150
Vermont	226	381	515
Virginia	186	420	715
Washington	913	1,087	1,265
Wisconsin	1,691	1,797	1,985
TOTALS:	9,633	15,656	22,806

The additional seven states developing programs after 1986 (Arizona, Arkansas, Illinois, Michigan, North Carolina, North Dakota and Oklahoma) brought the FY 1987 total served to 16,590 and the FY 1988 total to 24,817. Cumulative reported wages of these workers have grown from \$1.4 million to over \$12 million in less than two years in the 15 states that reported earnings data.

(Source: Wehman, Kregel, Shafer, & West, 1989)

Growth in the Number of Supported Employment Workers in 20 States 1986 - 1988

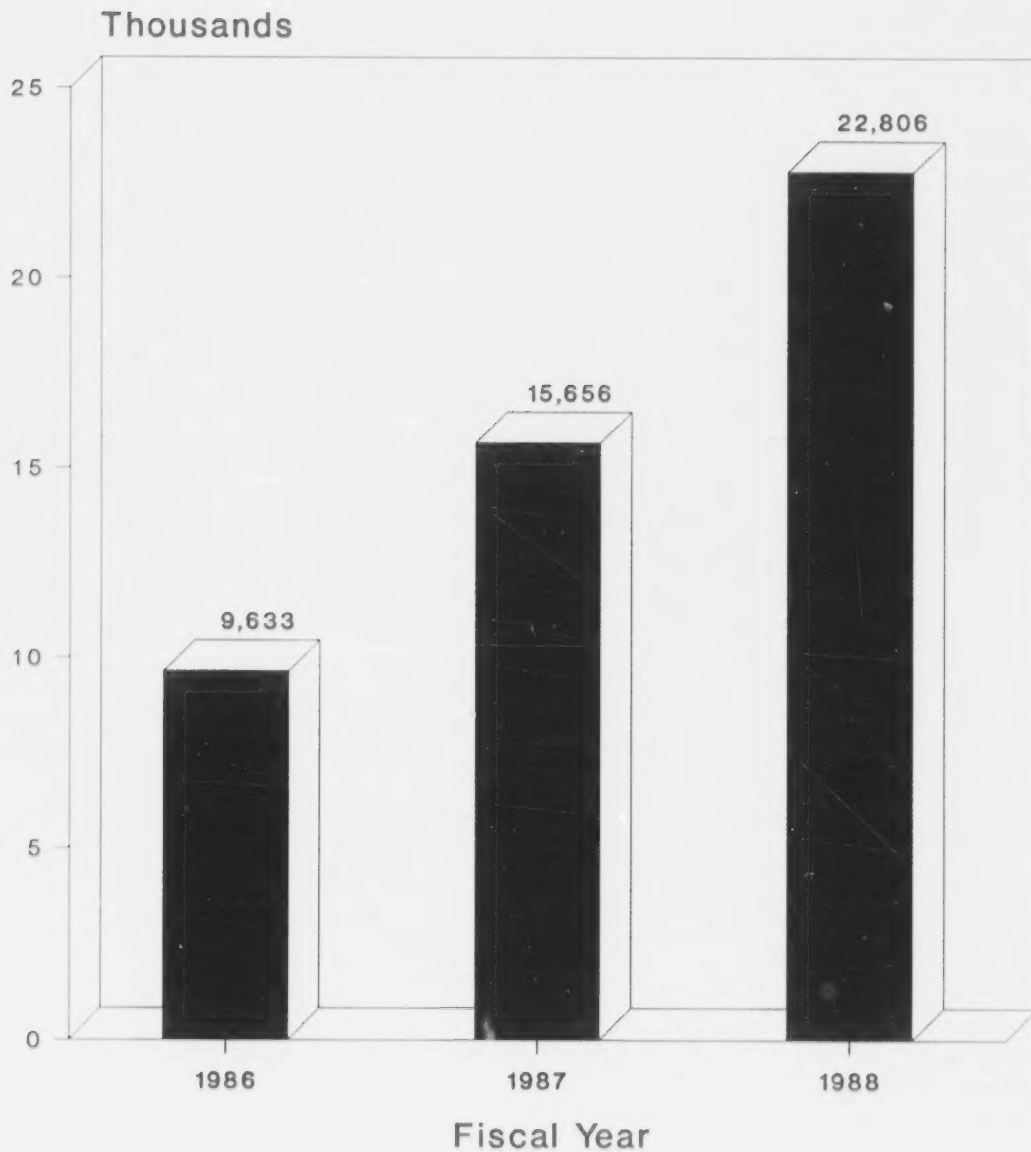
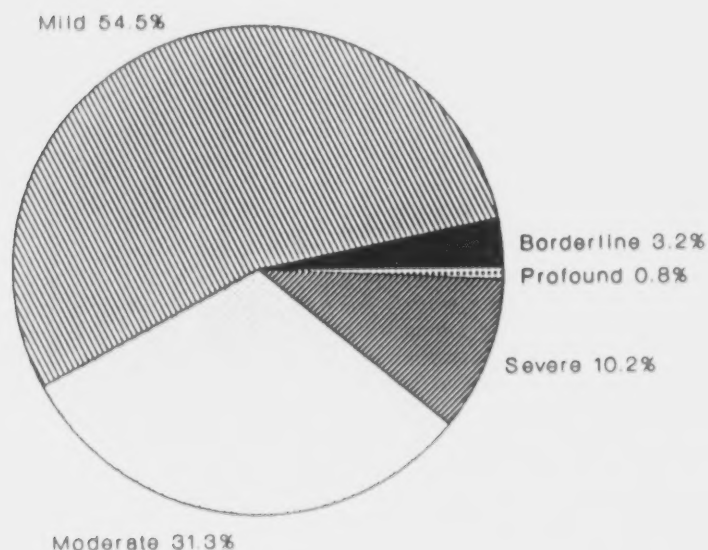


Figure 4.4 **Individuals in Supported Employment by Level of Mental Retardation**



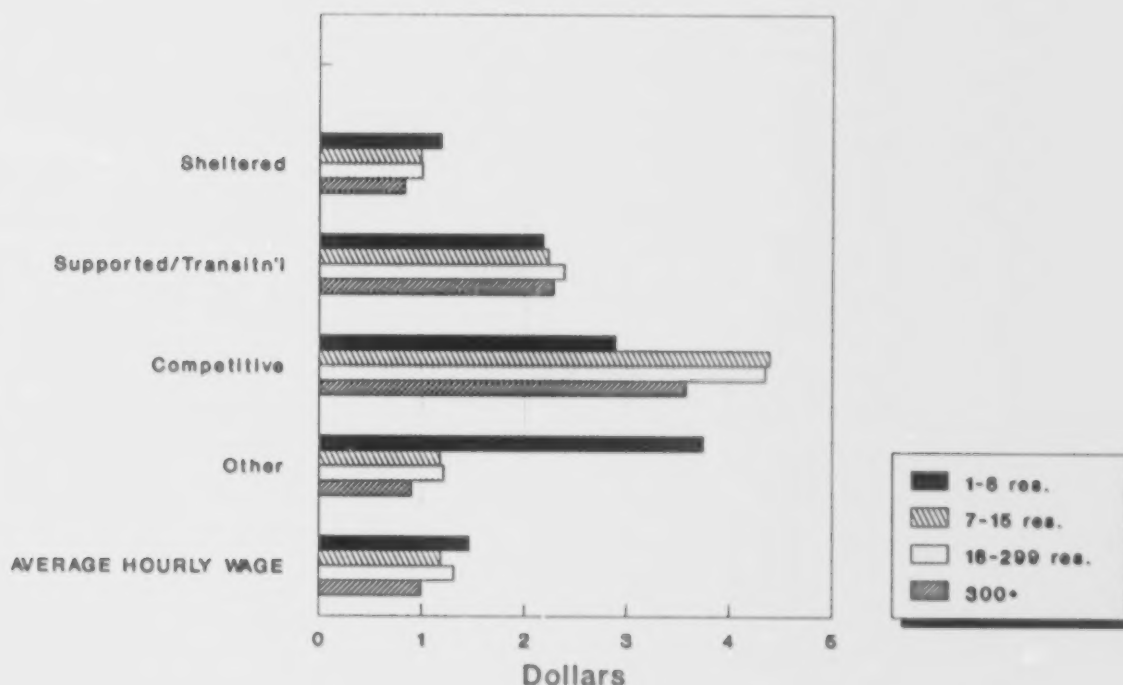
The 27 state supported employment systems change demonstration projects funded by the Office of Special Education and Rehabilitative Services (described in 4.3) have reported the types of disabilities of the workers in their supported employment programs. The majority are reported to have mental retardation (71.6%). The second largest group is made up of people with long-term mental illness (14.6%). Other groups with less than 2% representation each are those with autism, hearing impairment, traumatic brain injury, and visual impairment.

Of the workers with mental retardation in supported employment, 54.5% were reported to have mild mental retardation and 31.3% were reported to have moderate mental retardation. Only 10% were classified as severely mentally retarded and 1% as profoundly mentally retarded.

In terms of types of occupation, 22.5% of the supported employment workers were in the food service industry, 34.9% were in cleaning and custodial work, and the remainder were in clerical, manufacturing, and other types of work.

(Source: Wehman, Kregel, Shafer, & West, 1989)

Figure 4.5 Hourly Wages of Persons in Mental Retardation Facilities by Type of Employment and Size of Residence in 1987

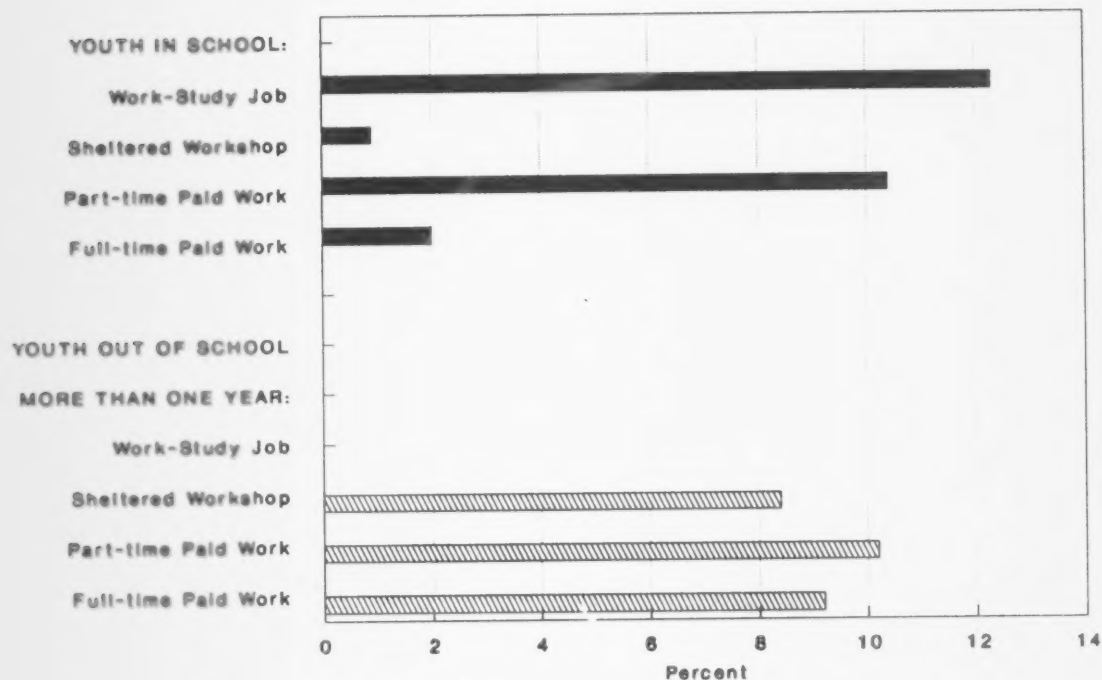


For residents of mental retardation facilities, the estimated average hourly wage for paid work was \$1.25 in 1987. Average wages varied relatively little by the size of their residence; employed residents of small facilities averaged \$1.29 per hour and residents of large facilities averaged \$1.21 per hour.

Across all sizes and types of residences, there was a strong association between wages and type of employment. That is, the amount of money people earned was more associated with type of employment than with the size of the facility in which they lived. People in all size facilities worked in all types of employment conditions. People in sheltered work averaged \$1.02 per hour, varying from \$1.06 per hour for residents of small facilities to \$.98 per hour for residents of large facilities. People in supported employment averaged \$2.15 an hour, and in competitive employment \$3.87 an hour. Although people in nonsheltered work arrangements earned considerably more than sheltered employees, the fact that over two-thirds of the workers living in MR/DD facilities were placed in sheltered work settings contributed substantially to the low overall average wages for all workers.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 4.6 Percentage of Youth with Developmental Disabilities Who Are Employed

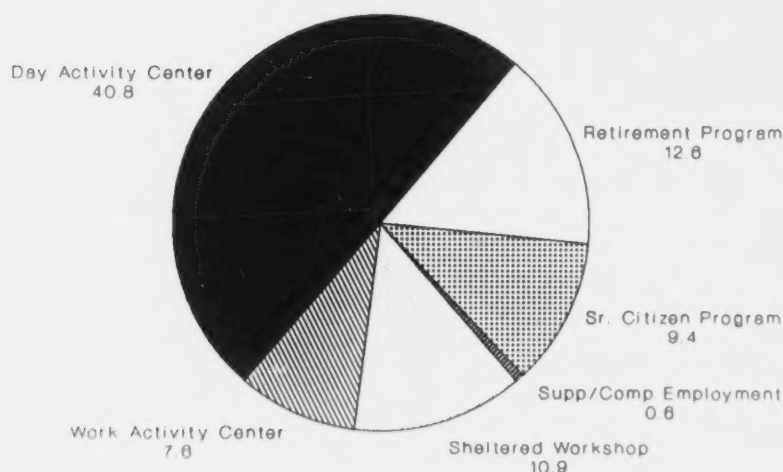


The U.S. Office of Special Education and Rehabilitative Services has been conducting a five-year longitudinal study of special education students as they make the transition from school to further education, employment, and independent living. This National Longitudinal Transition Study (NLTS) followed over 8,000 youth with handicaps to determine their occupational, educational, and independent living status after leaving special education programs. Students in school were compared with students out of school for more than one year. For students with disabilities, having paid employment during secondary school had a strong relationship to the ability to obtain a paid job upon leaving school. However, national employment levels for youth with developmental disabilities were markedly below employment rates for youth without handicapping conditions, as well as below employment levels for all students with handicapping conditions. In the general population of youth 16 to 21 years of age and not in secondary school, 62% worked for pay, compared with 46% of all youth with handicapping conditions. Only 20% of students with developmental disabilities were employed for pay. Another 8.4% were in sheltered workshops.

Of the students who worked for pay, 41% worked more than 35 hours a week, 23.5% worked between 21 and 34 hours a week, 14.7% worked between 10 and 20 hours a week, and 20.6% worked less than 10 hours a week.

(Source: Office of Special Education and Rehabilitation Services, 1989)

Figure 4.7 Day Programs of Elderly Persons in MR/DD Facilities in 1986



In recent years as normalized life styles have been stressed for persons with developmental disabilities, a great deal of attention has been given to the educational experiences of children and youth and the vocational experiences of working age adults. Less attention has been given to the lifestyles of persons with MR/DD of retirement age, who, like older people generally, are a growing segment of the population. A 1986 study looked at the daytime activities of a national sample of 370 persons 63 years or older living in MR/DD facilities. Sample members participated in a great variety of day programs, with approximately equal numbers participating outside (44.2%) and inside (40.8%) their facilities, but with about 15% reported to have no day program. The majority of residents of foster homes, group homes, and large private facilities who were involved in day programs attended programs outside their facility, while residents in state institutions were more likely to attend programs within the institution (58%).

For persons attending external programs, the majority (40.8%) attended day activity centers. Options available included programs offered through developmental disabilities funding, such as work activity centers (7.6%), sheltered workshops (10.9%) and supported/competitive employment (0.6%), but also programs available to senior citizens generally, such as senior citizen programs (9.4%) and retirement programs (12.6%). A wide range of programs was reported for the remaining 18% of persons engaged in day programs, including adult day care, therapeutic recreation, parks and recreation activity centers, adult basic education classes, and adult recreation/socialization programs. The number of weekly hours of participation in these programs varied widely, from only a few hours a week to 30-40 hours a week.

(Source: Anderson, Lakin, Bruininks, & Hill, 1987)

PART V: How are people with disabilities and their families being empowered?

Living as part of a community means more than a house in a residential neighborhood or a relatively small number of housemates. Along with the increased commitment to a physical presence in community settings for persons with developmental disabilities, there has been increased emphasis on improving opportunities for people to develop and maintain as normal a lifestyle as possible, to fulfill valued roles within the culture, and to maximize self-direction, which after all is a cornerstone of our society. Increased acceptance of such ideals has in turn caused virtually every element of the service system to reconsider both its practices and its perspectives. Significant changes and challenges have occurred as these new views of what life ought to be for persons with developmental disabilities come into conflict with existing service systems.

Earlier charts have shown what these changes have meant in terms of living arrangements, schooling, and employment opportunities. An equally if not more important aspect of these changing perspectives has been the gradual empowerment of people with disabilities and their families to speak for themselves, select services for themselves and even to purchase those services for themselves. As fewer families look to out-of-home services, as the movement toward consumer-controlled housing and services grows, and as society expands its recognition of the rights and capabilities of persons with disabilities through legislation like the Americans with Disabilities Act, recognition of the ability of people with developmental disabilities and their families to speak for themselves and act in their own behalf is growing. The following charts show the current status and indications of important trends in the empowerment of people with developmental disabilities and their families to speak and make decisions on their own behalf.

Figure 5.1 Summary of State Family Support Activities

During the 1980s, needs of families became of greater concern in state and national policy deliberations. In particular, attention was given to the social and economic implications of supporting rather than supplanting families. Several new federal initiatives, including Medicaid Home and Community-Based services and Medicaid eligibility for non-poverty families with children with developmental disabilities, provided important services to people living with their families. Many other family support programs have been developed by state and local agencies to assist families in maintaining their children in the family home.

In 1988 and 1989 the University of Illinois at Chicago conducted a comprehensive state-by-state analysis of the number of recipients and costs of discrete state programs to provide family support services in Fiscal Year 1988. In 1989, the Human Services Research Institute conducted a survey of the 50 states to determine the scope and breadth of state family support programs. The following table summarizes the findings of these surveys regarding the types of supports available to families in each state, the number of families served (nearly 143,000 nationwide), and the total revenue for family support programs (about \$171,000,000 in FY 1988).

The primary types of supports provided to families include:

Respite care. Respite care is intended to give a family a temporary break from the demands of caring for a child with a significant impairment. It is the oldest and most generally available family support service and is provided by 46 states. States exhibit a wide range of options and flexibility in their programs, from a maximum of 10 days a year of a single option in one state, to a variety of options in other states, including child care support and assistance in finding sitters for all the children in the family.

Financial Assistance. This type of support is administered in widely differing ways. Options include: (1) direct cash payments with few restrictions on the use of funds and the expectation that families will use them to purchase virtually all the support services they need; (2) a combination of access to an array of formal family support services, but with supplemental financial aid to allow families to obtain supports beyond those offered, but often with restrictions on what families are allowed to purchase; (3) financial assistance provided in the form of service vouchers, which families use to make purchases from the available range of services.

Services. A total of 38 different services were identified as being offered, with ranges from none to 27 different allowable services in any one state. Next to respite, the most frequently identified support services are adaptive equipment (31 states) and family counseling (27 states). Others include different therapies, medical services, health and nutrition services, special clothing, recreation, home modifications, home repairs, flexible payment for any disability related expense, and case management.

Combination. Seventeen states use a combination of financial assistance and direct services to support families.

(Sources: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990; Knoll, Covert, Osuch, O'Conner, Agosta, Blaney, & Bradley, 1990)

SUMMARY OF STATE FAMILY SUPPORT ACTIVITIES

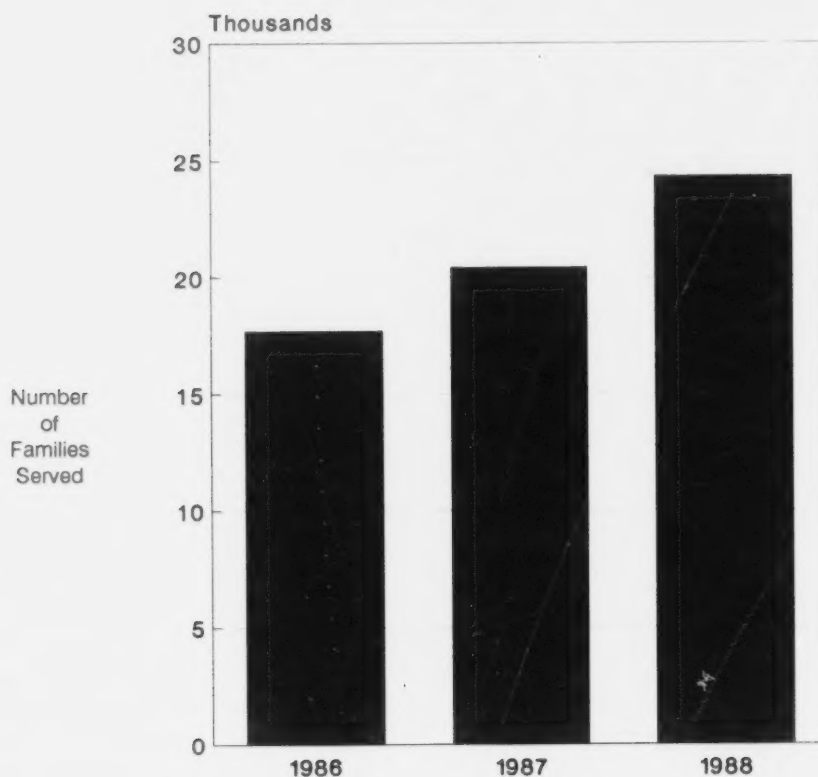
State	Type of Support*				Families Served	Current Funding (FY 1988 Dollars)
	Respite	Financial	Services	Combination		
Alabama	•				443*	325,000
Alaska			•		436	718,000
Arizona	•	•			1,781	3,975,900
Arkansas		•			40	206,000
California			•		32,913	30,511,839
Colorado		•			315*	289,894
Connecticut	•	•			1,492	1,903,409
Delaware	•				266	80,352
Dist. of Columbia	•		•		430	493,082
Florida			•		11,336*	11,285,234
Georgia				•	1,056	611,562
Hawaii		•			400	115,000
Idaho	•	•			372	113,500
Illinois	•			•	12,050	12,315,500
Indiana			•		1,000	370,542
Iowa		•			0	0
Kansas			•		0	0
Kentucky			•		3,541*	2,732,957
Louisiana	•	•			169	45,743
Maine	•				500	197,306
Maryland			•		2,008	4,050,136
Massachusetts	•		•		13,000*	18,900,000
Michigan		•	•		3,300*	14,679,251
Minnesota		•			400*	2,680,700
Mississippi*					0	0
Missouri	•				500	536,655
Montana		•	•		1,755	2,844,400
Nebraska		•			0	0
Nevada	•	•			70	162,200
New Hampshire			•		1,285	936,174
New Jersey			•		N/A	8,793,000
New Mexico	•				224	187,000
New York			•		20,000	16,536,000
North Carolina			•		1,395	1,072,900
North Dakota	•	•	•		802*	777,200
Ohio		•			4,646*	3,562,462
Oklahoma			•		0	0
Oregon				•	0	0
Pennsylvania				•	15,639	10,086,219
Rhode Island	•	•	•		175	1,700,000
South Carolina		•			241	1,422,100
South Dakota†					0	0
Tennessee			•		187	104,860
Texas		•			3,649	9,642,856
Utah			•		55*	447,100
Vermont	•		•		420	588,500
Virginia				•	900	2,466,094
Washington			•		2,500	2,500,000
West Virginia			•		N/A	114,850
Wisconsin				•	3,428	2,524,160
Wyoming		•			0	0
U.S. TOTAL					142,673	171,107,307

* From Knoll et al. (1990). Other statistics from Braddock et al. (1990).

† No distinct family support initiatives. Some service to families provided through general funding of developmental services.

Δ No distinct family support initiatives. Some service to families provided through the state's pilot early intervention project.

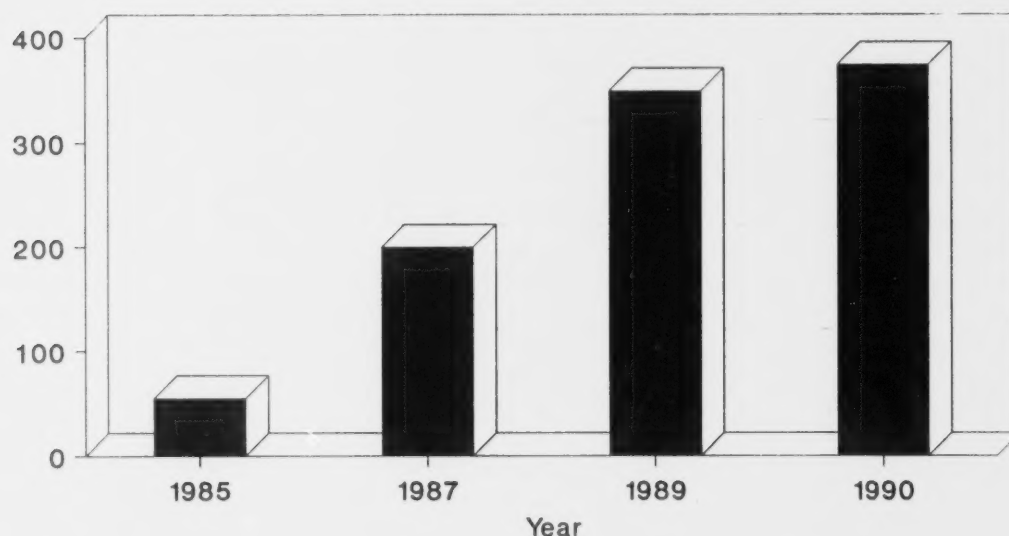
Figure 5.2 **Growth in Families Receiving Respite Care Services in 30 States over a 3-Year Period**



Respite care is the most common service provided to families with children with developmental disabilities. Respite care provides families caring for members with developmental disabilities occasional opportunities for a temporary break from those demands. Almost all states (46) report that respite care is available to families in their state. In FY 1988 thirty-three states reported that state MR/DD funds were specifically budgeted for respite care. These funds totalled approximately \$50,500,000 and assisted 50,369 individuals and their families. Many local government agencies also fund respite care services, for an unknown number of families. In the 1988-1989 University of Illinois at Chicago survey of states, thirty individual states were able to provide the multi-year statistics on changes in the number of respite care recipients from FY 1986 to FY 1988. Those states reported a 37% increase in respite care recipients over the three year period.

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

Figure 5.3 The Growing Number of Self-Advocacy Groups for Persons with Developmental Disabilities



Since the first People First Convention in Oregon in 1974, attended by 560 people, the self-advocacy movement has grown in every state and throughout the country. Determining the actual degree of participation is difficult, since it is almost exclusively a grass-roots movement. Definitions of self-advocacy by self-advocates include:

"Self-advocacy means people with developmental disabilities speaking up and speaking out for their rights. . . . People with developmental disabilities should have the right to speak up and teach other people about their rights Speaking out can be taking a risk. Sometimes you're afraid a staff person might say no Self advocacy is about having choices." (Pat Killius, Michael Kennedy, Deborah Olson, Center on Human Policy, Syracuse University)

"Through the self-advocacy movement, people with developmental disabilities strive to achieve basic human rights and responsibilities. Self-advocacy means deciding what is best for you and taking charge of getting it. It is a movement of and by people with disabilities for themselves -- and thus is the means for the most far reaching and lasting impact on their lives and the lives of all around them. Self-advocacy provides enormous opportunity to people who have traditionally been given very few choices or input in their lives." (Bernard J. Carabello, Executive Director, Self-Advocacy Assn. of New York State, Inc.)

Beginning in 1985, the national office of the Association for Retarded Citizens began keeping a directory of known self-advocacy organizations. With names and addresses solicited by mail through local ARC chapters and People First organizations, the directory has reflected the growing number of these groups--from 55 in 1985, to 200 in 1987, 349 in 1989 and 374 in 1990.

(Source: Association for Retarded Citizens of the United States, 1990)

Figure 5.4 Results of the National Survey on Consumer Satisfaction

In what was undoubtedly the greatest effort ever to empower Americans with developmental disabilities and their families to speak on their own behalf, in the 1987 amendments to the Developmental Disabilities Assistance and Bill of Rights Act, Congress required each state's Developmental Disabilities Planning Council to undertake a thorough review of services, including a survey of the satisfaction of the consumers of these services. As part of this effort, 54 of the 56 states and territories participated in a coordinated national effort managed by the University Affiliated Program at Temple University, under the auspices of the National Association of Developmental Disabilities Councils. Two years of effort resulted in face-to-face interviews with 14,282 consumers. At present interview data are available on 13,075 people with developmental disabilities and/or their family members, representing roughly 1 out of every 200 people with developmental disabilities in America.

The Consumer Satisfaction Survey data will be used to respond to the fundamental question posed by the Congress in 1987: How satisfied are people with the various services they receive? A series of detailed reports around that question are being formulated by the Temple University researchers, with the results to be contained in the 1990 report to Congress.

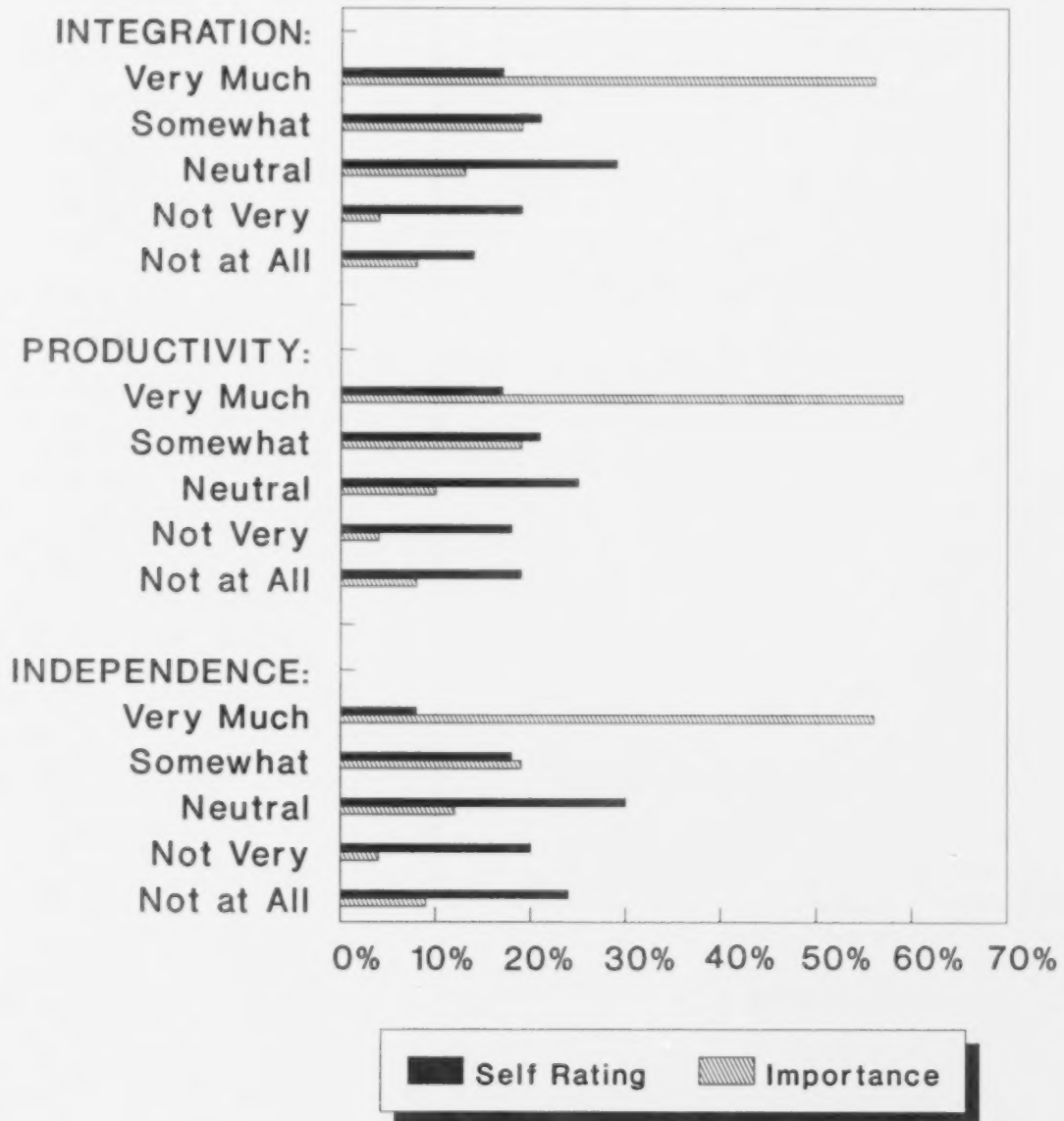
The figure presented here presents consumers' answers in three important areas. Federal legislation and state priorities through their Planning Councils on Developmental Disabilities have focused on increasing the integration, productivity, and independence of persons with developmental disabilities. Each consumer participating in the consumer survey was asked about his/her current status in each of these areas ("How integrated do you think you are?" "How productive do you think you are?" "How independent do you think you are?"). Then each person was asked how important that priority was to him/her. ("How important is it to you to be integrated?" "How important is it for you to be productive?" "How important is it for you to be independent?") Consumer responses to these questions are presented in the following figure.

Overall, between 75 and 80% of consumers considered being integrated, productive, and independent to be important to their lives. For the majority of persons who viewed these priorities as very important, their current life experiences failed to provide them with the levels of integration, productivity or independence they desired. Only about 25% of consumers either did not value these priorities or provided neutral responses regarding their importance.

In the area of integration, respondents were particularly likely to express a need for recreation and leisure services (55%). Transportation services were also reported to be needed by a majority of interviewees, including 23% who needed them to participate in leisure activities. With respect to productivity, 90% of respondents over the age of 16 indicated they were able to be workers and 57% said it was very important to be productive. However, only 17% actually considered themselves very productive. With respect to independence, adult respondents frequently noted their lack of involvement in the major decisions in their lives. For example, 70% of the interviewees with mental retardation and 41% of the other adults in the survey reported not having participated in the decision about where they live. Remarkably only 11% of the National Consumer Survey's respondents were people living in institutional settings of 16 or more residents, showing how much is left to be accomplished in making people with developmental disabilities part of their own communities.

(Source: Conroy & Feinstein, 1990)

Results of National Survey on Consumer Satisfaction



PART VI: What are the outcomes of community living?

In the past quarter century there has been a steady increase in the number of people with developmental disabilities remaining in and returning to natural communities. These changes have been driven by a number of basic legal, social, philosophical and psychological forces operating at different times and in different ways. These have included: 1) public exposes on poor conditions existing in many institutions; 2) research indicating that institutional settings by their nature provide lifestyles that are depersonalized and debilitating; 3) heightened awareness of the basic civil rights of people with developmental disabilities and associated court rulings; 4) greatly strengthened parent and consumer advocacy for community services; and 5) increased access to federal support for community based services.

Of course, underlying the massive national commitment to community services has been the assumption that in substantial ways people with developmental disabilities will be better off living in the community. It is assumed that in important ways they will experience a better quality of life than they did or would have in an institutional setting. Indicators of a better quality of life are often difficult to isolate, but they include that people with developmental disabilities and/or their parents will be more satisfied with community living, that people with developmental disabilities will experience significant developmental progress as part of living in the community, and that other positive social experiences will derive from living in a community setting. The following charts present data on a few important outcomes of community living for citizens with developmental disabilities.

Figure 6.1 The Impact of Community Living on Daily Living Skills and Problem Behavior

In the debates at federal, state and agency levels about the extent to which community services should replace institutional care, a recurring issue is the relative effects of community versus institutional care on the skills and behavior of individuals with developmental disabilities. Several comprehensive studies have addressed this issue.

From 1977 to 1988, 18 of these studies assessed changes in the adaptive behavior (basic skills of daily living) of individuals moving from state institutions to community living arrangements. All these studies met the following criteria: (1) followed at least 5 individuals from public institution placement through at least 6 months of living in a community facility of 15 or fewer residents; (2) collected baseline data while persons were still in the institutions; (3) measured overall adaptive behavior and/or specific types of adaptive behavior (e.g., self-care, domestic, communication, social skills) in the same manner and with the same instruments in both the institutional and community settings; and (4) discharged community-based subjects from institutions in or after 1975.

Two different major types of studies have been conducted: experimental/contrast group studies and longitudinal studies. The experimental/contrast group studies compared changes in daily living skills of persons who moved to the community settings (experimental group) with changes in the same skills of persons with similar characteristics who remained in the state institutions (control group). The skills of both groups were assessed at the same times before and after the experimental group moved. The longitudinal studies assessed the daily living skills of a single group of people before or at the time of deinstitutionalization and then 6 months or longer after the move. In addition 10 of these studies simultaneously gathered data on changes in problem behavior of the subjects of the research.

The results of these studies are shown in three areas: (1) change in overall adaptive behavior scores; (2) change in one or more specific types of adaptive behavior; and (3) change in problem (maladaptive) behavior.

Of the 18 studies, 13 noted statistically significant improvement in either overall adaptive behavior or in the basic self-care/domestic skill area. Another four showed a tendency, though not statistically significant within the particular studies, toward improved adaptive behavior. Only one study noted any decrease in any specific domains of adaptive behavior, in this case small statistically nonsignificant decreases in the "vocational" and "recreation/leisure" domains.

Among the studies of maladaptive, or problem, behavior, no consistent pattern of change was associated with the movement from institutional to community settings. One study showed statistically significant improvements, and four others showed a tendency for improvement but not at a statistically significant level. One study showed a statistically significant increase of problem behavior, with two others showing that tendency but not at a statistically significant level. Two others showed no change or mixed results among different groups of subjects.

(Source: Larson & Lakin, 1989a)

STUDIES OF BEHAVIORAL OUTCOMES ASSOCIATED WITH MOVEMENT FROM STATE INSTITUTIONS TO SMALL (15 OR FEWER PERSONS) COMMUNITY LIVING ARRANGEMENTS

First Author	Date	State	Study Type	Subjects	Age	Time (mos)	Level of Mental Retardation				Behavioral Outcomes		
							Mild	Mod	Sev	Pro	Adaptive Behavior Change		
											General Overall	Specific Domains	Problem Behavior
Bradley	1986	NH	E/C	80/80	AC	72	X	X	X	X	++	o,d	-
Bradley	1986	NH	Long	93	AC	84	X	X	X	X	++	++ d	-
Close	1977	OR	E/C	6/6	A	12			X	X		++ a	
Colorado	1982	CO	Long	108	AC	12	X	X	X	X	+		
Conroy	1982	PA	E/C	70/70	A	24	X	X	X	X	++		+ ¹
Conroy	1985	PA	Long	383 ²	AC	72 ²	X	X	X	X	++		+
Conroy	1988	CT	Long	207	A	24	X	X	X	X	++	++ d	--
D'Amico	1978	WV	E/C	6/7	AC	6.12 ³	X	X	X	X	++ ⁴ ++ ⁵	++a,b,c,f o d,e	
Eastwood	1988	N.E. USA	E/C	49/49	A	60	X	X	X	X		++a,c,d,e,f,g + b	
Feinstein	1986	LA	Long	158	AC	9	X	X	X	X	++		++
Horner	1988	OR	E/C	22/23	AC	60	X	X	X	X		++ a,c,f	+
Horner	1988	OR	Long	23	AC	60	X	X	X	X		++ a,c,f	+
Kleinburg	1983	NY	Long	20	A	12		X	X	X		+a ⁶ ,b,c - d,g	+ ⁷ - ⁸
O'Neil	1985	NY	Long	27	A	9	X	X	X	X		o a,b ⁹	
Rosen	1985	AR	E/C	58/58	A	24	X	X	X	X	++	++a,d,e,f	
Schroeder	1978	NC	E/C	19/19	A	12			X		++	+a,b,c	
Thompson	1980	MN	Long	5	A	24			X	X	+ ¹⁰	+ a,b,c,f,g ¹⁰	
Wisconsin	1986	WI	Long	24	A	18	X	X	X	X		++b,c,d,f +a,c	o

¹The movers problem behavior stayed the same while the contrast group's got worse.

²This study included 6 groups, all of which showed significant gains; the largest group measured over the longest time is reported here.

³After measuring behavior at 6 months, 2 of the control subjects were randomly assigned to move to the community.

⁴Time 1 (4 exp., 9 cont.)

⁵Time 2 (6 exp., 7 cont.)

⁶Domestic activities increased significantly, but domestic behavior showed no overall change.

⁷IQ above 20.

⁸IQ below 20.

⁹Significant increases were found in 4 of 16 subcategories in these skill areas.

¹⁰Mean differences were not tested for statistical significance.

Adaptive Behavior Domains

- a = self-care, domestic
- b = communication/language
- c = social skills
- d = vocational
- e = academic
- f = community living
- g = recreation/leisure

Age

- A = adult
- C = children
- AC = adults and children

Type of Study

- E/C = Experimental/Contrast
- Long = Longitudinal

Subjects = No. of Experimental Subjects/No. of Control Subjects

Outcomes

- ++ = statistically significant improvement after move to the community
- + = improvement after but not statistically significant
- o = no change after move
- = decline after move but not statistically significant
- = statistically significant decline after the move to the community

Figure 6.2 Integration of People with MR/DD Living in Small Community Residences into Community Life

Although many more individuals with developmental disabilities are living in small, community-based settings today than in years past, this does not in itself assure meaningful integration into the daily life of the community. There is a difference between being *in* the community and being a part *of* the community. A recent national study of community participation and integration of 336 persons with developmental disabilities living in community-based residential facilities of 6 or fewer people compared findings with a survey of a national random sample of 100 Americans. Four dimensions of integration into community life were examined:

1. **Domestic:** involvement in selected domestic-centered routines and activities of a typical community household, such as cleaning house, shopping for groceries.
2. **Vocational/Educational:** involvement in selected vocational and educational routines and activities typical for members of the community, such as employment, attending regular classes.
3. **Recreation/Leisure:** involvement in the use of selected community facilities, resources and programs for leisure or recreational activities.
4. **Social:** involvement in the typical social networks and potential relationships of the community, such as giving, receiving support, advice, or assistance, and visiting neighbors.

Community involvements of subjects with developmental disabilities in community residences and the national comparison sample were scaled so that each individual's level of community integration could range from 1.0 (highly integrated) to 0.0 (highly isolated). People with developmental disabilities, even when living in small community residential facilities, were generally not as well integrated into the life of the community as members of the general population. This was particularly evident in the vocational/educational and social dimensions of community living. In those areas, the lives of community facility residents with developmental disabilities were dramatically different from those of the members of the national sample. With the exception of foster home residents, the community facility residents with developmental disabilities had about as much domestic involvement as members of the general population. They actually experienced greater recreation/leisure integration than members of the general population, perhaps reflecting a perceived facility responsibility to assist residents in participating in community activities.

(Source: Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989)

Integration into Community Life

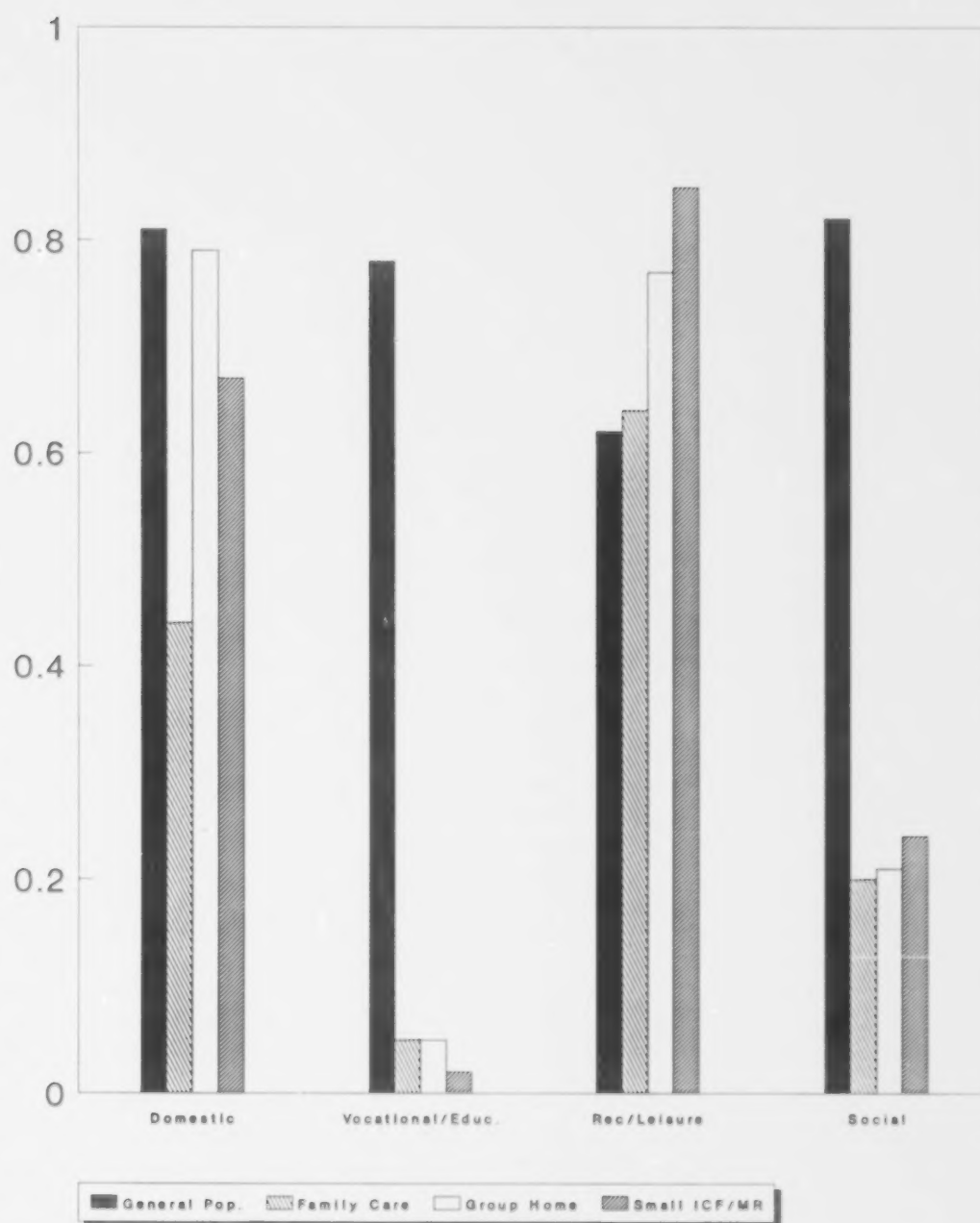


Figure 6.3 Parent Attitudes about Residential Placements: Parents Sampled during Institutional and Community Placement

Authors	State	Number	Residence ¹		Satisfied with Institution			Opinion Regarding Move			Satisfied with Community		
			Institutional	Community	Positive	Neutral	Negative	Positive	Neutral	Negative	Positive	Neutral	Negative
Conroy et al. (1985, 1987)	PA	472	•		83	11	7	14	14	72			
		369		•							88	6	6
Eastwood (1985)	MA	32 ²	•		92	3	5	32	18	50			
		38		•				88	6	6	84	6	9
Feinstein et al. (1986) ³	LA	11	•		70	30	0						
		53		•				43	28	29	81	19	0
Heller et al. (1986)	IL	184	•		93	—	7	25	—	75			
		126		•							97	—	3
Weighted mean % A ⁴			•		85.4	10.9	6.8	14.9	14.2	71.8			
Weighted mean % B ⁵				•				61.8	18.8	19.4	89.0	7.5	5.6

¹ This column indicates whether the person with mental retardation was living in a public institution or a community-based setting at the time the parents were surveyed.

² This study used an institutional contrast group that was not the same as the community group.

³ These studies asked how satisfied the respondent was with his/her relative's residence, while the others in this set asked about satisfaction with the care/programming/services.

⁴ These means reflect opinions of parents surveyed during institutionalization.

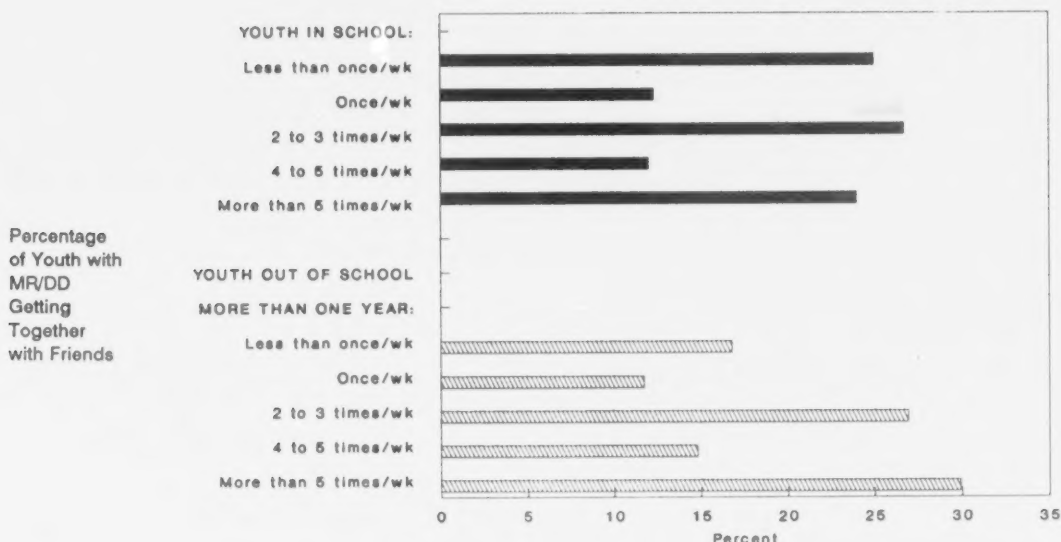
⁵ These means reflect opinions of parents surveyed during community placement.

Often, when it is proposed that a person move from an institution to a community residence, parents express opposition. This opposition appears to reflect both concern about the safety and quality of care in community settings, as well as parents' general satisfaction with the care of the family member in the institution. However, several research studies have demonstrated that once the child does move, dramatic changes occur in parental attitudes.

The four studies summarized here surveyed parents both before and after their family members moved from an institution to a community residence. All of these studies found high levels of satisfaction with the institution prior to the move (85.4%) and with the community residence after the move (89.0%). Of particular interest was the finding that when parents were questioned while their child (usually an adult child) was in the institution prior to community placement, only 14.9% had positive opinions about the proposed move. But when these parents were asked after the child had moved to the community regarding their initial opinions about the move, 61.8% of the parents recalled that they had been initially positive about community placement. One possible explanation of the apparent contradiction is that parents, once they have had the opportunity to see their family member in a small community arrangement, have a different frame of reference and a new perspective about the relative quality of life in the institution with which they were once satisfied. Once having seen the nature of the community residences, the institution may not have looked as good as it once did.

(Source: Larson & Lakin, 1989b)

Figure 6.4 Social Relationships and Activities of Youth with Developmental Disabilities



The National Longitudinal Transition Study (NLTS) sponsored by the U.S. Office of Special Education and Rehabilitative Services is a five-year longitudinal study of special education students as they make the transition from school to further education, employment, and independent living. Part of this study is an examination of aspects of the social lives of youth with disabilities, both in school and after they leave school.

A common social experience of students with developmental disabilities was involvement with individual friends. While in school, almost 70% of students reported getting together with friends at least once a week. After youth were out of school more than one year, this percentage increased to almost 80%.

While in school, 33% of students with developmental disabilities were affiliated with some school or community groups. However, the rate for these students was lower than the overall rate for all students with disabilities (43%). Only an estimated 22% of students with developmental disabilities out of school more than one year belonged to an organized school or community group.

Other measures of social integration found 7% of students with developmental disabilities out of school more than one year were married, engaged or living with someone of the opposite sex. This compared to 12% of all youth with disabilities out of school more than one year.

Among youth with developmental disabilities, an estimated 4% of those still in school and 7% of students out of school more than one year, had been arrested. This compared with 9% of all youth with disabilities who were still in school and 21% of those out of school for more than a year.

(Source: Office of Special Education and Rehabilitation Services, 1989)

PART VII: How much do services cost?

Determining the cost of services for persons with developmental disabilities presents many complex problems. There are well over a hundred federal programs providing funds for services, and even more numerous state and local sources, all of which are supplemented with considerable private funding and voluntary support. Computing the costs of specific programs can be nearly as complex as determining the aggregate expenditures for services in general. Large institutions determine costs in ways often appreciably different from smaller community-based programs. In cost comparisons, it must be recognized that a range of complex factors contribute to the costs of care, including the severity of disability of program clientele, the location of service, the nature and intensity of services offered, and a range of other factors. Despite this complexity, it is simply not possible to ignore the overall costs of services for persons with developmental disabilities, the amounts of funding allocated to different types of services, or differences in the costs of specific models of care and support. Clearly knowledge about the costs of services is essential to creating better incentives for the provision of the most appropriate care. As the General Accounting Office pointed out in a 1977 report, "The most important question [about cost] appears to be how to most cost effectively serve mentally disabled persons in the least restrictive environment appropriate to their needs."

During the 1980s, the amount of public funding devoted to care for persons with mental retardation and related conditions increased significantly, reaching about 12 billion dollars in 1988, *excluding* education and certain entitlements. That growth was primarily, although not exclusively, in the number of dollars spent for community-based services. This section presents information on a variety of topics related to the overall financing of services for persons with developmental disabilities and comparative costs of different types of services.

Figure 7.1 MR/DD Spending for Large Residential and Community Services, 1977-1988

Total state and federal funding for services to persons with mental retardation/developmental disabilities has increased from \$3.5 billion in 1977 to nearly \$11.7 billion in 1988. Adjusting for inflation, this represents an increase of 72% in twelve years. These increases reflect the continued rapid expansion of community services with relatively little "real dollar" expansion in fiscal commitment to institutional care (16% increase). From 1977 to 1988, adjusted expenditures (i.e., controlled for inflation) for public institutional care increased only 6%. In contrast, adjusted community services expenditures increased 225% over the same period. Expenditures grew most rapidly for large private institutions (293%), although total large private facility expenditures made up only about 8% of all MR/DD expenditures nationally. Between 1986 and 1988, the total dollars spent for institutional care (i.e., services to people living in public and private facilities of 16 or more residents) increased from \$5.5 billion to \$6.1 billion. In the same period, community services funding increased from \$4.1 billion to \$5.7 billion. But the small increases in institutional expenditures went for continually decreasing numbers of persons, as the average per person cost of care in large facilities continued to increase steadily.

The tables below compare expenditures for institutional and community services. "Community services" encompass a much wider array of services than institutional care, including residential and habilitation services for persons living in places with 15 or fewer other residents; but also supported employment, family support, early intervention, and other state assisted services.

		1977	1986	1988	Percent Increase	
					1977-1988	1986-1988
Nominal Dollars	GRAND TOTAL	\$3,461,460,571	\$9,614,092,723	\$11,716,825,830	238%	22%
	Public Institutions	\$2,461,323,585	\$4,731,991,323	\$5,142,491,178	109%	9%
	Large Private	\$120,916,677	\$796,288,759	\$936,952,404	675%	18%
	Community	\$879,220,309	\$4,085,812,641	\$5,637,382,248	541%	38%
Constant 1988 Dollars	ADJUSTED GRAND TOTAL	\$6,819,077,325	\$10,383,220,141	\$11,716,825,830	72%	13%
	Public Institutions	\$4,848,807,462	\$5,110,550,629	\$5,142,491,178	6%	1%
	Large Private	\$238,205,854	\$859,991,860	\$936,952,404	293%	9%
	Community	\$1,732,064,009	\$4,412,677,652	\$5,637,382,248	225%	28%

		1986	1987	1988	Adjusted Percent Increase		
					1986-1987	1987-1988	Average
Nominal Dollars	Large (16+) Residential	\$5,528,280,082	\$5,766,819,720	\$6,079,443,582			
	Community	\$4,085,812,641	\$4,831,270,314	\$5,637,382,248			
Constant 1988 Dollars	Large (16+) Residential	\$5,970,542,489	\$6,055,160,706	\$6,079,443,582	1.4%	0.4%	0.9%
	Community	\$4,412,677,652	\$5,072,833,830	\$5,637,382,248	15.0%	11.1%	13.0%

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

MR/DD Spending for Large Residential and Community Services, 1977-1988

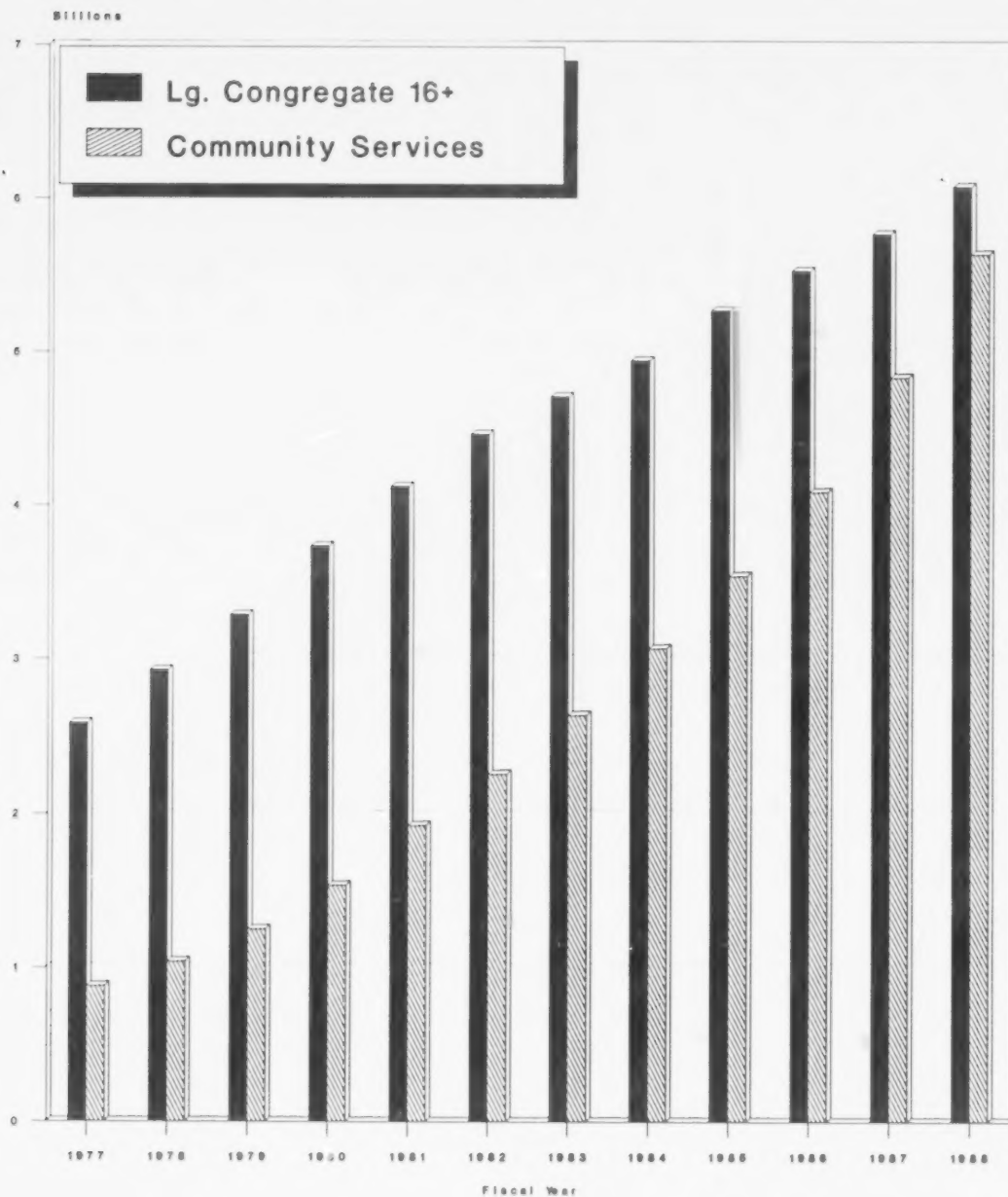


Figure 7.2 Title XIX Federal Medicaid Expenditures for Persons with Mental Retardation and Related Conditions

The Intermediate Care Facility for the Mentally Retarded (ICF-MR) program under Title XIX (Medicaid) of the Social Security Act is by far the largest source of federal support for services for persons with MR/DD. On June 30, 1988, about 146,100 persons with MR/DD were living in ICFs-MR, representing 54% of all persons in MR/DD facilities nationwide. Another Medicaid option, Medicaid Home and Community Based Services, has, since its enactment in 1981, also become a significant program for persons with MR/DD. On June 30, 1988 it had a total of about 28,700 service recipients. Although Medicaid programs for persons with MR/DD are criticized for maintaining a high level of participation in, if not bias toward, institutional care, there clearly has been increasing use of federal Medicaid options to support community-based residential and alternative services. In 1977, federal Medicaid funds for ICFs-MR were almost exclusively devoted to large institution care (98.6%). By 1982, the proportion of Medicaid funding for community services (small public and private facilities, and Home and Community Based Services) had increased to 5.8%. In 1988, funding for community options represented 21.9% of total federal Medicaid MR/DD long-term care expenditures.

Between 1977 and 1982, federal ICF-MR funding for large public residential settings more than tripled (a 208% increase), but the rate of growth between 1982 and 1988 slowed to 35%. Federal funding for large private ICFs-MR grew even more rapidly, increasing from about 33 million dollars in 1977 to 209 million dollars in 1982, and then more than doubling again by 1988 to 451 million. Federal funding for community services grew tremendously between 1977 and 1988, from less than \$10 million to nearly \$800 million. The overall increases in this 11 year period for Medicaid ICF-MR and Home and Community Based Services are shown below.

	1977	1982	1988
Large Public ICFs-MR	573,486,028	1,765,579,789	2,387,401,701
Large Private ICFs-MR	33,173,664	208,792,586	450,513,621
Small Private ICFs-MR	8,878,210	104,722,809	443,439,416
Small Public ICFs-MR	0	14,953,335	100,031,208
Home & Community Based Services	0	1,244,000	251,708,930
TOTAL	615,537,902	2,095,292,519	3,633,094,876

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

Title XIX Federal Medicaid Expenditures for Persons with Mental Retardation and Related Conditions

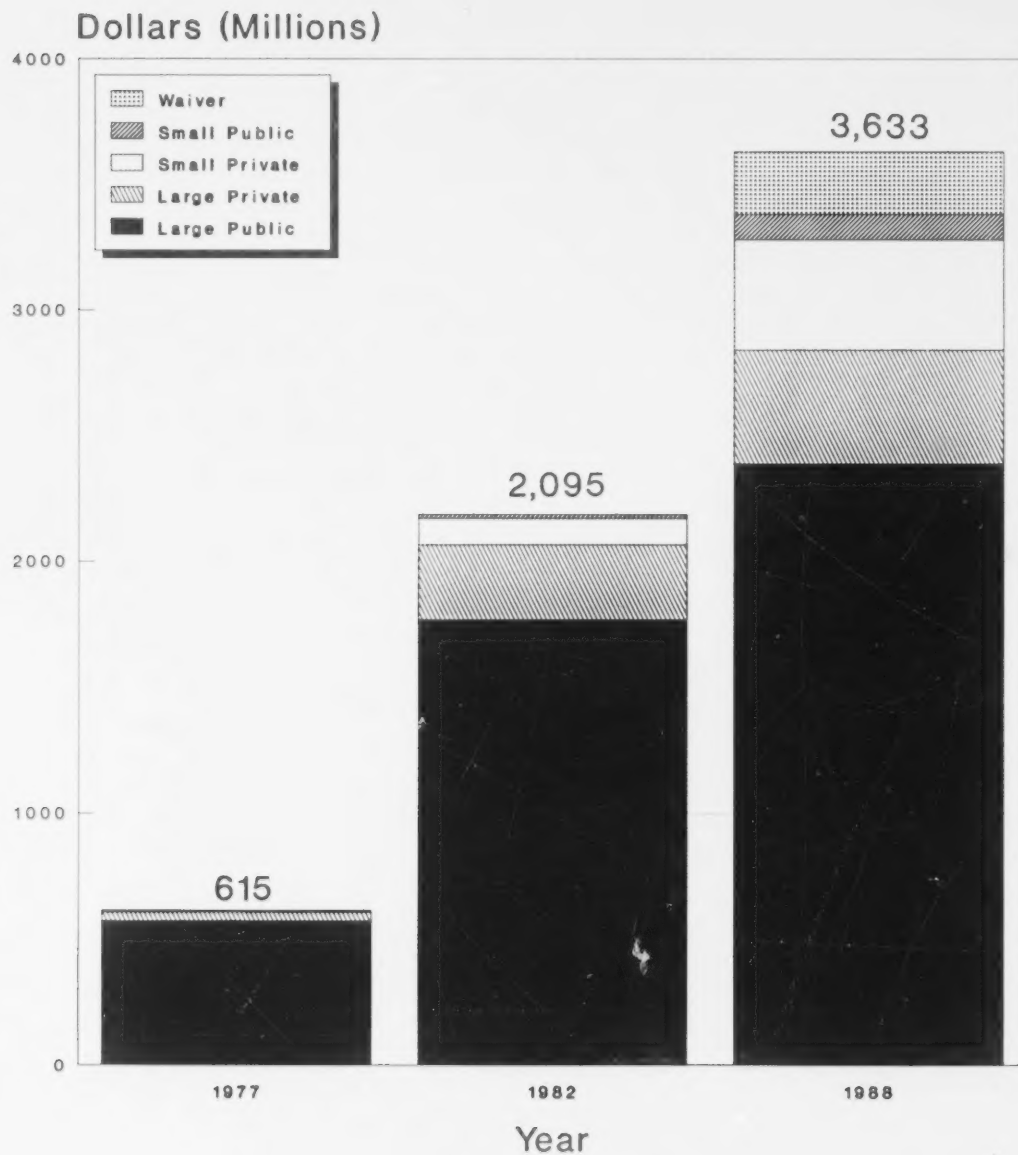
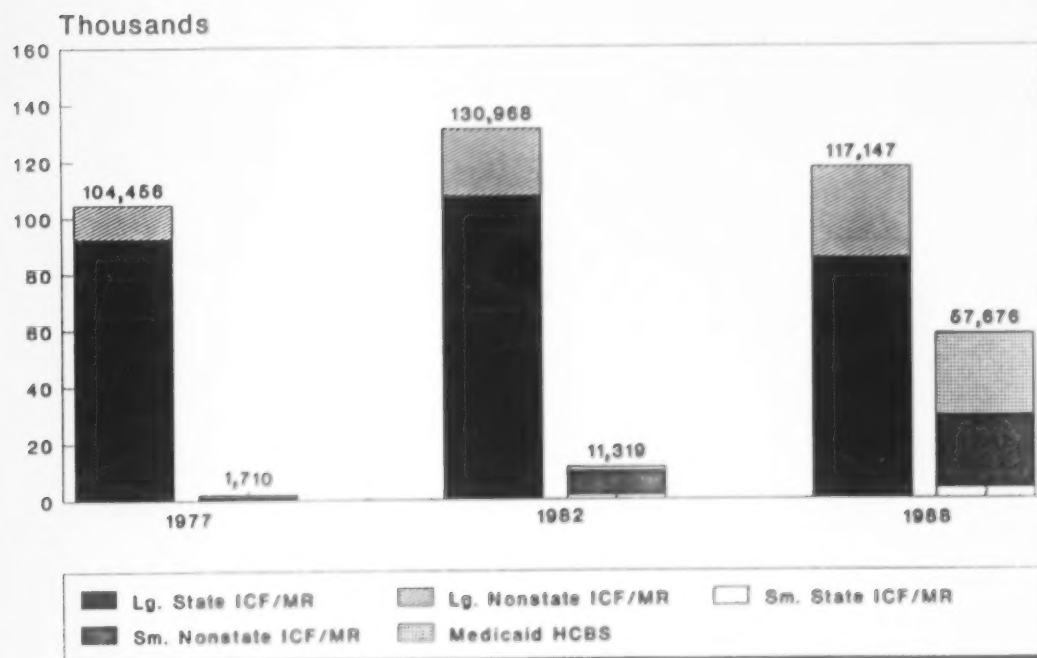


Figure 7.3 Institutional and Community Recipients of Medicaid ICF-MR and Home & Community-Based Services Benefits in 1977, 1982, and 1988

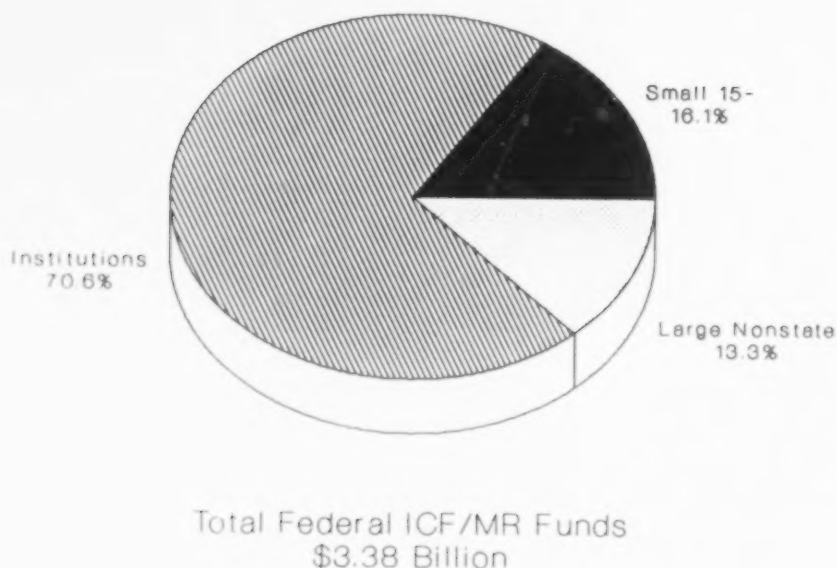


From 1977 to 1988 there was a dramatic increase in Title XIX (Medicaid) service recipients living in smaller community-based settings, that is, people living in Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) of 15 or fewer residents or receiving Medicaid Home and Community-Based Services (Medicaid waiver). Community-based recipients increased from 1,710 on June 30, 1977 to 57,676 on June 30, 1988. Over the same period, the number of institutional recipients of ICF-MR care (i.e., in places with 16 or more residents) rose from 104,456 in 1977 to 130,966 in 1982, and then decreased to 117,147 by June 30, 1988.

In 1977, the total proportion of ICF-MR recipients being served in community-based settings was 1.6%. In 1982, the proportion of small, community ICF-MR and Medicaid Home and Community-Based Services (HCBS) recipients made up 7.8% of all ICF-MR and HCBS recipients. By 1988, small community ICF-MR and HCBS recipients represented 33% of all 174,823 Medicaid ICF-MR and HCBS recipients.

(Source: Lakin, Prouty, White, Bruininks, & Hill, 1990)

Figure 7.4 ICF-MR Spending by Facility Setting 1988

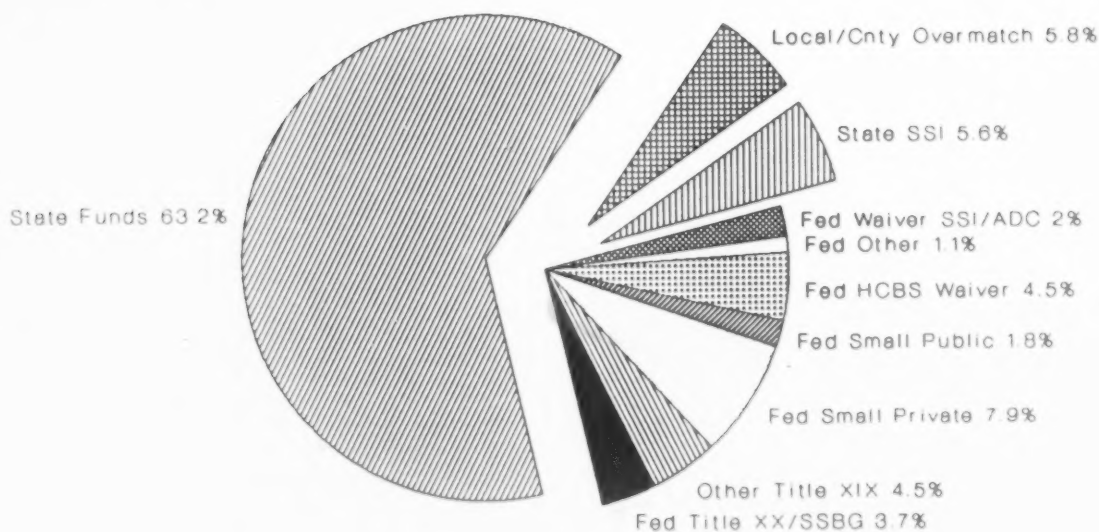


In the last decade, the financing of state institutions in the U.S. has shifted substantially toward federal support. For example, in 1988 states provided about 52% of the funds expended in state institutions, as compared with 74% in 1977. In 1988 almost 97% of federal contributions to state institution revenues were through the ICF-MR program, which in a majority of states (26) financed more than half of the total cost of state institution operations.

Federal and state ICF-MR contributions together made up over half (51.5%) of all noneducational MR/DD service expenditures in 1988. Most ICF-MR funding was used to finance large residential living arrangements of 16 beds or more. In 1988, 84% of ICF-MR funding supported large congregate care of 16 beds or more, with 71% of all ICF-MR funding used to support public institutions. Forty-two states used more than two-thirds of their ICF-MR budgets for funding placements in congregate care settings of 16 or more residents. Rhode Island was the only state which used most of its ICF-MR funds in facilities of 15 or fewer residents.

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

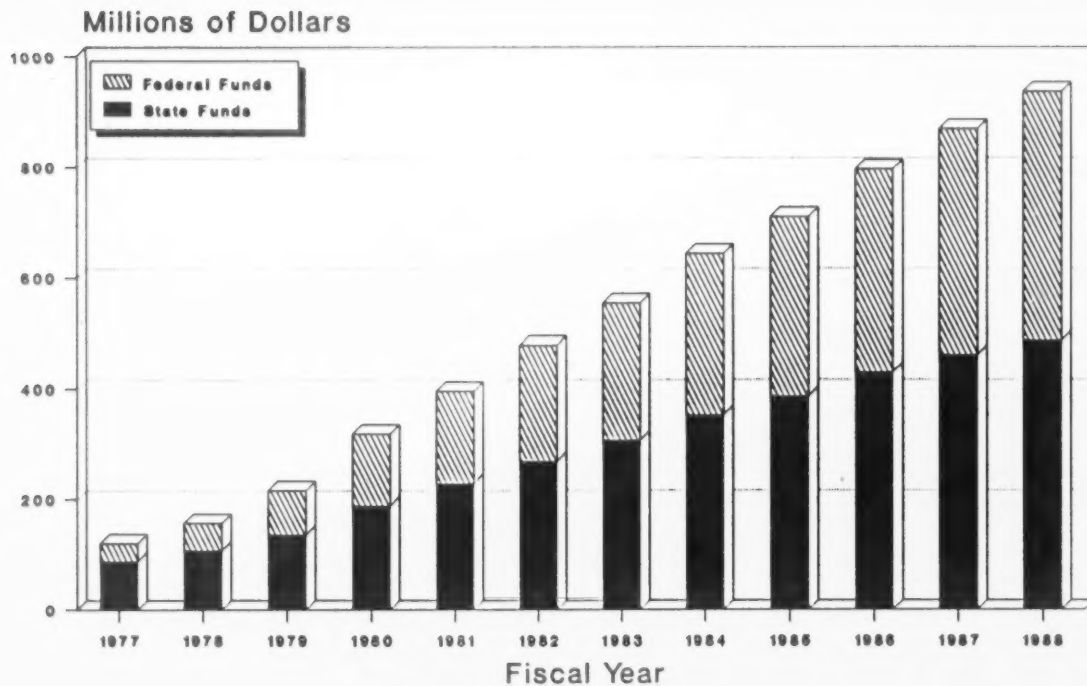
Figure 7.5 FY 1988 Total Community Services Revenue--\$5.637 Billion



The expansion of community services has been largely funded by state initiatives. In order to implement the full range of community services, states employ a variety of revenue sources. In 1988, the total amount spent for community services was approximately \$5,637,000,000. State government general revenue funding was the major source of monies for these services, representing 63.2% of total funds spent in 1988. State appropriated supplementation of SSI contributed about 6% to the total expenditures for community services; local and/or county overmatch represented another 6%; and the remaining 25% came from a variety of federal sources, including: federal ICF-MR funding of small facilities (9.7%), Medicaid Home and Community-Based Services (4.4%), other Medicaid service reimbursements (4.5%), Title XX Social Services Block Grant (3.7%), and other federal programs (3.1%).

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

Figure 7.6 Growth of Public Funding for Large Nonstate Residential Facilities



In terms of rate of change since 1977, public expenditures for large private institutions (i.e., facilities with 16 or more residents) have been growing more rapidly than public expenditures for either public institutions or community services. In 1988, \$937 million in public funds were expended for large private facilities, representing an 18% increase since 1986 in unadjusted terms, and a 675% increase since 1977. This rise has occurred despite generally stable total populations (about 49,800 in 1977 and 45,900 in 1988). A primary factor in this rapid increase in public funding has been the rapid growth in ICF-MR participation of large private facilities (from about 23% of total large private facility capacity in 1977 to 70% in 1988). In 1988, about 32,000 persons were served in large privately operated ICFs-MR of 16 beds and over, as compared with about 14,000 who resided in large non-ICF-MR private facilities. While the overall cost of participating in the ICF-MR program has been a factor of obvious importance in the increase in public expenditures for large private facilities, such participation has quite likely also had the effect of reducing overall private payments and contributions.

(Source: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990)

Figure 7.7 Average Annual per Resident Cost of Care in State MR/DD Institutions

The costs of care in state institutions (16 or more residents) for people with mental retardation and related developmental disabilities have increased dramatically since 1950. At that time, the annual cost of care in state institutions was about \$750 per resident. Thirty-eight years later, the cost of care in these facilities averaged over \$57,000 per person per year. In dollars adjusted for changes in the Consumer Price Index over this period, costs of care in 1988 were over 15 times as great as in 1950.

Several factors have contributed to these increasing costs, including:

- (a) the increasing level of impairment of the persons served in large state facilities, with an accompanying increase in the intensity and specialization of professional staff to serve existing residents;
- (b) decreasing access to and reliance on residents with less severe disabilities in operating and maintaining facilities;
- (c) court decisions and settlement agreements with frequent requirements to upgrade the quality of supervision, habilitation, and residential environments; and
- (d) federal and state legislative efforts to upgrade the quality of living and habilitation provided, including the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program enacted in 1971.

While the ICF-MR program, with its demanding program, staffing, and physical plant standards, has clearly contributed to the overall cost of state institution care, it has also significantly cushioned the impact of rapidly increasing costs on the states. For instance, from 1970 to 1988, the annual cost of care expressed in "constant" 1967 dollars rose from \$4,000 to over \$15,000. Of this \$11,000 increase in "real dollars," the state's share was less than \$3,000, with the federal contributions accounting for the difference.

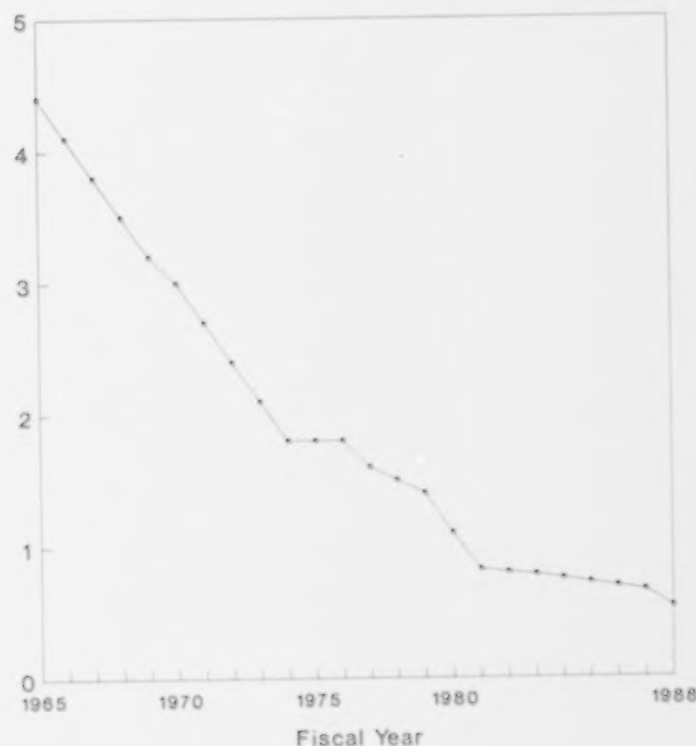
<u>Year</u>	<u>Cost</u>	<u>Cost (\$1 = 1967)</u>
1950	745.60	1,034.15
1955	1,285.50	1,603.02
1960	1,867.70	2,104.90
1965	2,361.08	2,498.02
1967	2,965.33	2,965.33
1970	4,634.85	3,985.25
1974	9,937.50	6,728.17
1977	16,143.95	8,894.74
1980	24,944.10	10,127.30
1981	30,645.40	11,246.86
1982	32,758.75	11,400.04
1984	40,821.60	13,103.73
1985	44,270.85	13,723.96
1986	47,555.85	14,456.98
1987	54,516.40	15,755.24
1988	57,221.05	15,881.50

(Source: White, Lakin, & Bruininks, 1989)

Average Annual Per Resident Cost of Care in State MR/DD Institutions



Figure 7.8 **Change in the Ratio of Residents to Direct Care Staff in Public Institutions, 1965-1987**

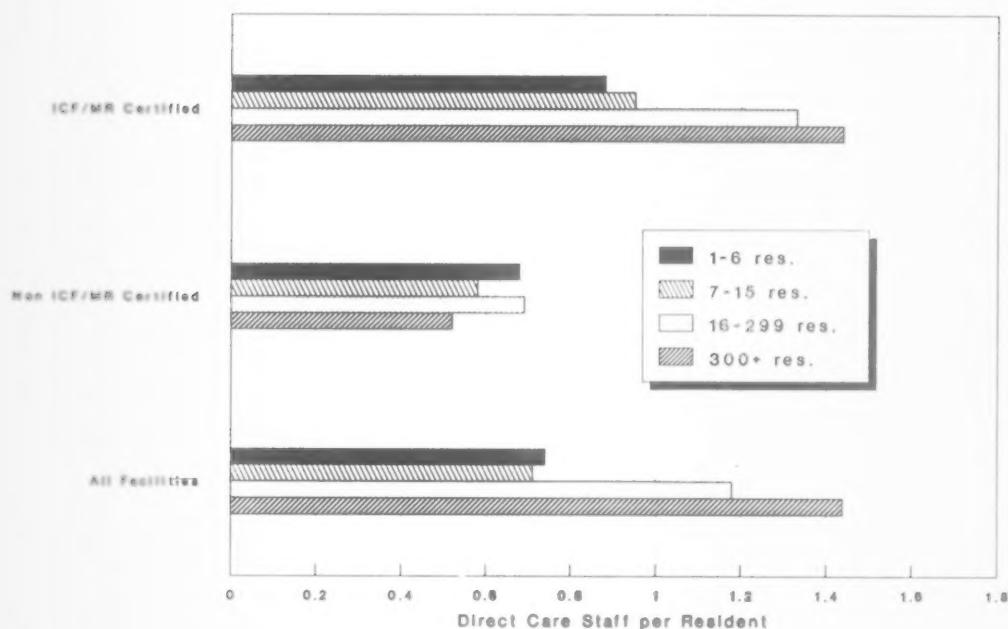


The largest proportions of costs in the care of persons with developmental disabilities are personnel costs. Payroll expenses (wages, payroll taxes and fringe benefits) generally make up about two-thirds of the costs of providing residential care. Public facilities tend to have somewhat higher proportions of their total costs comprised of payroll expenses, while private facilities have a somewhat lower proportion in personnel, often because of relatively higher capital costs for their newer facilities. The costs of residential care are highly sensitive to changes in personnel utilization. One factor affecting the dramatically rising costs of care in public institutions is the rapidly increasing ratio of direct-care providers to institution residents. That ratio has shifted from 4.4 residents to each direct-care employee in 1965, to .78 in 1981, to .53 in 1988.

The figures presented here do not represent the resident to staff ratio at any one time, but the average ratio of all residents to the total complement of direct-care staff expressed in full-time equivalent positions (approximately four 40 hour workweeks make up the 168 hours in a week). Factors affecting the dramatic shift in this ratio are higher standards for staffing ratios because of court and legislative mandates, the federal Intermediate Care Facility for the Mentally Retarded (ICF-MR) program standards, and the increased severity of impairment of state institution residents.

(Sources: Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990; Lakin, Bruininks, Doth, Hill, & Hauber, 1982; Lakin, Hill, Chen, & Stephens, 1989)

Figure 7.9 Direct Care Staff to Resident Ratios by Facility Size and Type



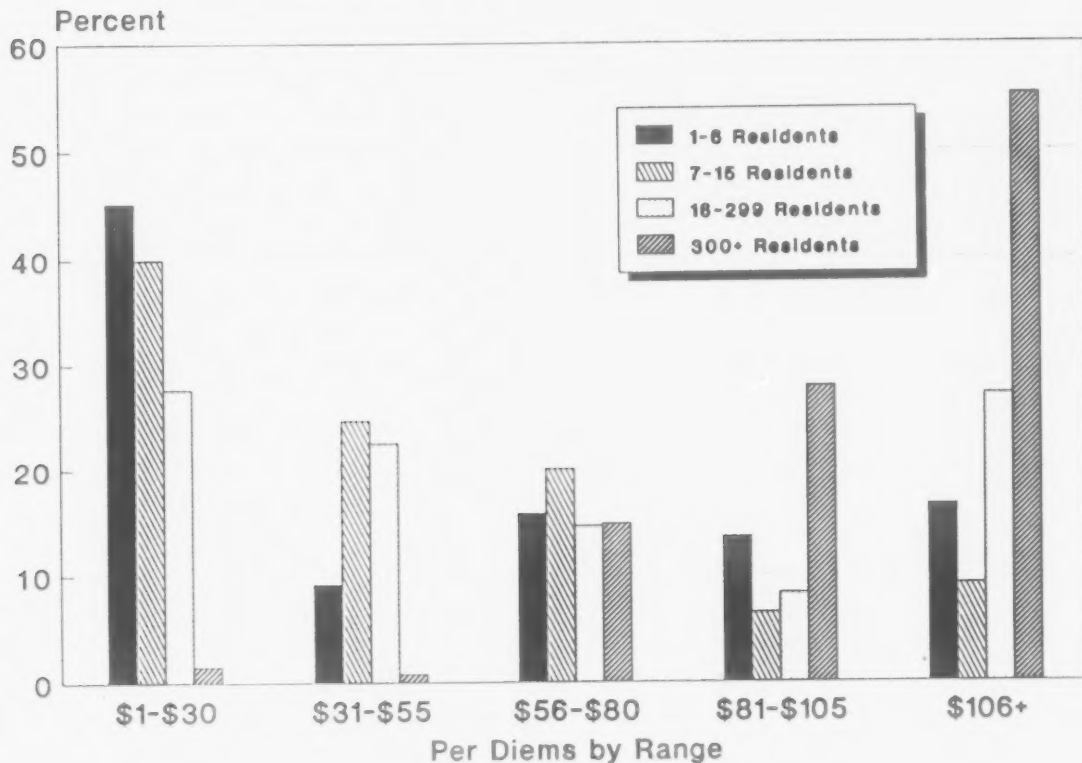
In addition to different services covered under facility reimbursement rates, staffing levels make a very substantial contribution to the costs of care. Substantial differences exist among facilities in their ratio of staff to residents, based both upon size of facility and certification as an Intermediate Care Facility for the Mentally Retarded (ICF-MR). Generally, the 1987 National Medical Expenditure Survey found that there were now more people providing care nationally than are receiving it (1.06 direct care staff:1 resident). But with 168 hours in a week and the prevailing 40 hour work week, this ratio translates to an average of 4 residents to 1 direct care staff at any one time.

Ratios of staff to residents were much higher in ICF-MR certified facilities (1.33:1) than among non-ICFs-MR (.66:1). Smaller ICFs-MR had much lower staff to resident ratios than larger ICFs-MR (.92:1 and 1.41:1, respectively). Small facilities in general had lower staff to resident ratios than larger facilities, except among non-certified facilities. One factor contributing to lower ratios in small facilities was the fact that in many of the smaller proprietary facilities the owner/operators lived in the facility (as their own home) and were providing care and supervision for considerably more time than the 40 hours per week that would constitute a single full-time direct care position in a shift-staffed facility. A factor in the generally higher staff-resident ratios in ICFs-MR was the fact that residents of these facilities tended to have more extensive needs for care and supervision than residents of non-ICFs-MR.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 7.10

Daily Reimbursement Rates for Facilities by Facility Size

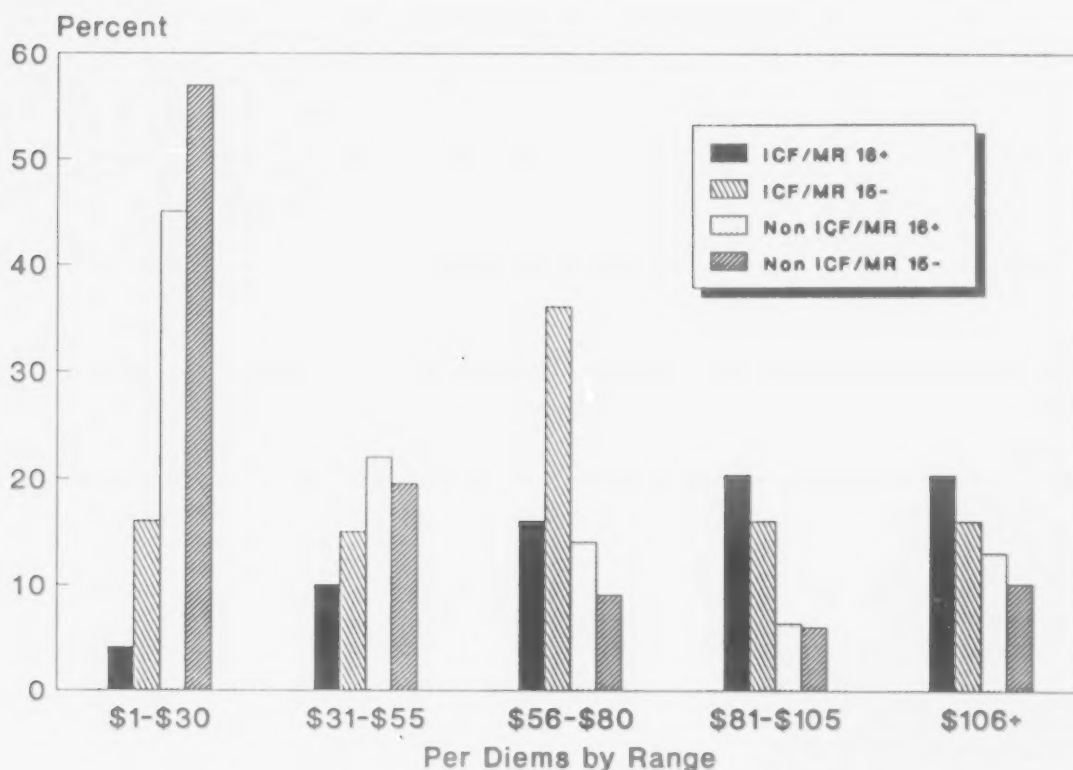


The daily cost of residential care varies greatly from facility to facility. Generally, daily costs range from \$15 a day to well over \$300 per day, and facilities of all sizes have a wide range of daily reimbursement rates. In general, the smallest facilities have the lowest reimbursement and the largest facilities have the highest. In 1987 an estimated 45.2% of the people living in facilities of 1-6 residents were living in places with per diem reimbursement rates in the range of \$30 or less per day, as were 39.9% of people living in facilities with 7-15 residents. In contrast, only 1.5% of the people living in facilities with 300 or more residents were in places with rates of \$30 or less per day. Among the largest facilities (those with 300 or more residents), 55.2% of residents were living in places that had daily reimbursement rates of \$106 or more. In contrast, 16.5% of the residents of facilities with 6 or fewer residents and 9.1% of facilities with 7-15 residents were living in places with reimbursement rates of \$106 per day or more. In comparing reimbursement rates, it is important to recognize that institution reimbursement rates often include significant costs not included in the rates of smaller facilities, notably the cost of day programs and medical services that are often provided as part of the general program of the larger residential facilities but not in smaller facilities.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 7.11

Daily Reimbursement Rates for Facilities by Size and ICF-MR Certification



Facilities which are certified under the Intermediate Care Facilities for the Mentally Retarded (ICF-MR) program, regardless of operator or size, tend to have higher per diem reimbursement rates than non-certified facilities. Among private for-profit facilities, 83% of residents in non-certified facilities were in residences with a daily reimbursement rate of \$55 or less, compared with only 51% of residents of ICFs-MR. Among nonprofit facilities, 64% of residents in non-certified facilities and 35% of those in ICFs-MR were in residences with a reimbursement rate of \$55 or less. Among government operated facilities, 21% of non-certified facility residents were in places being reimbursed at \$55 or less per day, as compared with only 1% of persons in public ICFs-MR. An estimated 65% of public and private ICF-MR facility residents were in places with reimbursement rates of \$81 or more per day, compared with only 18% of the residents of non-certified facilities.

(Source: Lakin, Hill, Chen, & Stephens, 1989)

Figure 7.12

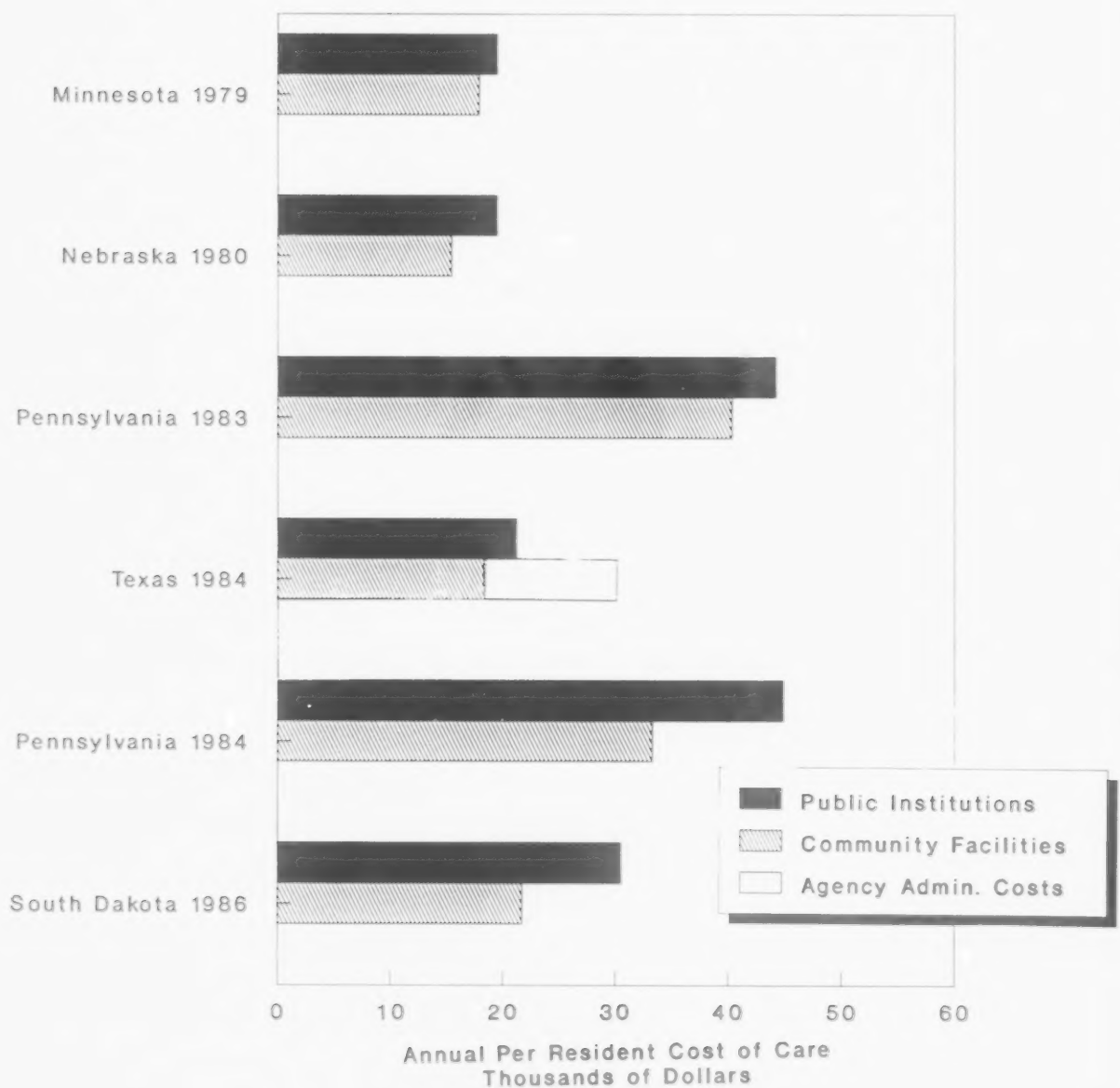
Studies Gathering Comparable Cost Data on Residents of Public Institutions and Community Residential Facilities

In the discussion of the two preceding figures, it was noted that comparison of reimbursement rates across facility types and sizes is often confounded by the fact that institution costs frequently include the costs of services not provided by smaller residential providers (e.g., day programs, medical services). There have been a limited number of studies that have tried to compare institutional costs with the costs of a similarly comprehensive community-based "package" of residential and other related services. In examining the summary of these studies below, it may be noted that 1) overall administrative costs are less easily and, in the case of these studies, less often attributed to community facilities than they are to public institutions (see the Texas study for the possible effects of doing so); and 2) residents of institutions are generally more severely impaired than residents of community facilities, although the Pennsylvania and South Dakota studies attempted to control for these differences.

State/Author(s)	Residential Programs Compared	Types of Costs Included	Notes on Costs Included
Minnesota: Minnesota Department of Public Welfare (1979)	Public ICF-MR institutions and private community (ICF-MR) facilities	Residential, day programs, transportation, social services (case management, family support, etc.), medical services	Cost of components calculated only for individuals in private facilities, presumed covered in institution per diem. Institutional capital not included.
Nebraska: Touche Ross & Co (1980)	Beatrice State (ICF-MR) and community-based mental retardation (CBMR) programs (non-ICF-MR)	Residential, day program, support service (physical & speech therapy, transportation, etc.), social service (case management, social work), administration	Costs of components computed on a per client average from budgets of 6 CBMR regions. Beatrice State cost components extracted from facility budget. Medical costs for CBMR clients based on average of state Medicaid billings. Institution capital not included.
Pennsylvania: Jones, Conroy, Feinstein & Lemanowicz (1983)	Pennhurst State (ICF-MR) and community residential facilities (CRFs) with average bed size of 3.2 clients	Residential, day programs, entitlements, medical costs, case management, other	Study based on a matched sample of 70 former and 70 current residents of Pennhurst. Costs of components calculated for individuals in both CRFs & Pennhurst.
Texas: Bensberg & Smith (1984)	Public ICF-MR institutions and small (less than 15 res.) ICF-MR facilities	Residential (food, rent, utilities, phone, maintenance, staff), support services (day services, transportation)	Costs of components calculated only for individuals in small facilities, presumed covered in institution per diem. Institution capital not included.
Pennsylvania: Ashbaugh & Allard (1984)	Pennhurst State (ICF-MR) institution and community living arrangements (CLAs) with 3-6 residents	Residential, day programs, case management, specialized support services, medical and transportation	Costs of components calculated for individuals in both CLA and Pennhurst.
South Dakota: Campbell & Smith (1986)	All large public institutions and all community facilities (1-8 res., 9-16 res.)	Residential, day programs, case management, administration, medical services, follow-along services for each individual. Other costs prorated to individuals.	Actual costs computed for individuals in institutions and community settings, except "other" costs for each category of facility (e.g., training, monitoring) which were equally apportioned to each resident of the facility type.

(Sources: Ashbaugh & Allard, 1984; Bensberg & Smith, 1984; Campbell & Smith, 1986; Jones, Conroy, Feinstein, & Lemanowicz, 1983; Minnesota Department of Public Welfare, 1979; Touche Ross & Co., 1980)

Studies Gathering Comparable Cost Data on Residents of Public Institutions and Community Residential Facilities



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